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Protection From Harm: AIDS in Residential Facilities

by Betty Jane Chura

The Commission's work on sexuality and people with developmental disabilities had revealed that in some residential settings it was fairly common for a number of residents to be sexually active with multiple partners. The health-related implications were clear: add a sexually transmitted disease and the results could be devastating; add HIV and the results could be deadly. We knew it was only a matter of time before someone asked us for help in dealing with one of these situations.

> **Whether a program errs by doing no capacity assessments, presuming all residents are competent, or conversely determines that even very capable persons lack capacity to consent, it opens itself to liability and exposes its residents to jeopardy.**

The call came from the sister of a woman with mental retardation who had contracted AIDS while a resident of an OMRDD certified program. The caller had taken her sister home to care for her, but was very concerned about the well-being of the adult residents remaining at the facility, particularly those who were sexually active. She had spoken of her concerns to the agency administrators but was not confident that they were following-up appropriately to protect residents who may have needed their intervention. She reported that her sister's HIV+ partner was still residing there, and she had been informed that he was sexually active with other residents.

The Commission's initial investigation confirmed the concerns of the caller. There were serious questions about the safety of some residents who were sexually active. The facility had made no clinical assessments to identify those residents who did not have the capacity to consent to sexual activity and thereby required protection, and it had taken only limited efforts to identify those residents whose behaviors placed them at risk of contracting the HIV virus. It was also unclear whether all of the sexually active residents had been instructed in safer sex practices and even less certain whether they were using them.

The facility had arranged for individual professional counselling for the resident who was HIV+ and his present partner. The administration had also identified some persons at risk of contracting the virus because they had been involved in sexual activity with one of the residents known to be HIV+, and had secured consent for and had begun HIV testing for these individuals. But, as the Commission discovered, much more still remained to be done.

Earlier in the year, staff of the agency had suggested that all residents be evaluated and a determination for each resident be made of his/her capacity to consent to sexual activity. The facility administration had responded that such a practice was unnecessarily intrusive and violated the principles of normalization. The facility maintained this position until the Commission and the OMRDD became involved and asked the agency administrators to secure assessments on those residents whose capacity was questionable as a first step in providing needed protections. Similarly, although the facility had secured consent for and had begun HIV testing for several residents most obviously at risk, in response to the recommendations of the OMRDD and the Commission, the facility expanded the group of "at risk" residents to include the known partners of those who had had

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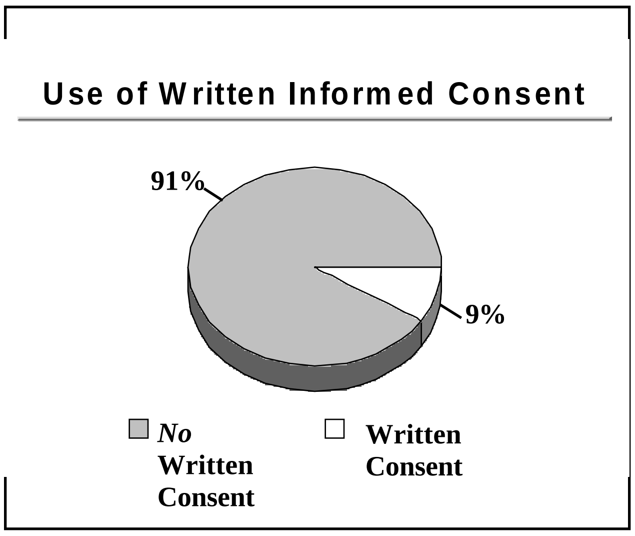
Commission Urges Parental Consent for Medication of Children In Psychiatric Hospitals



A fundamental protection that must be afforded every child in an inpatient psychiatric facility is the extremely careful prescription, administration and monitoring of psychotropic medications. In a study released recently, *The Role of Psychotropic Medication in the Treatment of Children in NYS Mental Health Inpatient Settings*, the Commission found that the majority of parents/guardians neither are adequately informed, nor is their permission sought before their children are administered psychiatric drugs in state-operated children's psychiatric facilities. To protect patient rights and involve families in treatment planning, the Commission report strongly recommends to the Office of Mental Health (OMH) that parents and guardians be given comprehensive information about psychoactive medication, and their written informed consent be obtained by psychiatric facilities before such medication is given to minor children.

Positive Findings

The Commission study revealed several positive features of medication management across all facilities, finding that these state children's psychiatric hospitals generally use safe prescribing practices in administering psychoactive medication, stay within dosage limitations, avoid unnecessary use of multiple medications, and monitor the side effects of medication. However, the study raised questions and concerns related to the fact that these facilities do not comply with existing OMH guidelines to provide children with "medication-free" periods to verify the continued need for such drugs. They also often resort to additional doses of medication to suppress outbursts of undesirable behavior, rather than involving clinical staff to manage children in crisis through individualized treatment plans.

In a statement accompanying the report, Commission Chairman Clarence J. Sundram said, "if one conceives of the medication prescribing and administration practices at the sampled facilities as the walls of a structure, they are, by and large, sturdy. But the study also revealed that the structure lacks a solid foundation: parents/guardians often have not given informed consent for the use of psychotropic medications with their children; physicians have not ensured medication-free periods to verify the chil-

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Inside

Counsel's Corner

Provider's Liability for Sexual Activity Which Causes Injury, Pregnancy or a Sexually Transmissible Disease

Paul F. Stavis

The sexual revolution, the litigation explosion in personal injury cases and the advent of new, deadly and incurable sexually transmissible diseases [STD] are combining to produce a new body of law for compensating the resultant physical and emotional injuries. Increasingly, our courts are being petitioned for awards of large amounts of money to compensate for damage caused by the transmission of sexual disease. The defendants in such cases can be individuals who, being infected themselves, have negligently or intentionally infected others. They can also be persons not directly involved, who can be held vicariously liable for the injury due to a special relationship with injured party or plaintiff. The latter cases may include providers, treatment professionals or licensees of mental hygiene programs.

There are many reasons for these failures to inform: 1) the person does not know he or she has the condition; 2) the person knows but negligently or intentionally fails to disclose; 3) the person should have known (due to lifestyle) of high risk; etc.

The last decade has seen ever increasing transmissions of sexual diseases such as herpes, AIDS, chlamydia and other venereal diseases. Because the infected partner more often than not fails to alert the prospective sexual partner of the possibility of such transmissions, the courts are applying traditional principles to hold them responsible to those they injure. When a person discovers that during sexual activity he or she has been infected and subsequently might develop a painful, stigmatizing, debilitating and sometimes incurable disease, which might also seriously affect reproductive ability, and was not told of this risk of infection, there is a natural desire to want compensation for the expenses of treatment and for the physical and emotional injury that was caused by their sexual partner.

Indeed, recent years have seen such public figures as the singer Tony Bennett, the comedian Robin Williams, the actor Rock Hudson, the prize fighter Mike Tyson, the basketball player Magic Johnson and others, sued for civil money damages for placing another person at risk or possibly transmitting a sexual disease to another person.[1]

The focus of this article is upon how these concepts of tort law might apply to persons with mental disability who are under the care of the state or one of its licensees. There are two very important elements of law to be considered which might involve providers, treatment professionals and licensees in such lawsuits. First, a provider of services is generally held to be responsible for protecting a person in their care from being harmed, which would certainly include sexual harm. Indeed, the right to protection from harm not only has a basis in the general civil tort law, but for a state and its licensees, it may also have a basis in the U.S. Constitution.[2]

The second is a concept of tort law called "vicarious liability," meaning a person can be held at least partially responsible for the injury, even if he is only indirectly involved in causing the injury and even though he is not the prime actor or most direct cause of the injury. For example, hotel operators have been held responsible for the rape of a guest for failure to have sufficiently secure locks on the doors of the hotel rooms; bar owners have been held responsible for serving drunk customers who later cause damage in driving or fighting; and perhaps most commonly, the owner of a car is usually responsible and liable for damage done by someone he allows to use it.

The purpose of this article is to explore the developing legal precedents created by lawsuits for sexual injury focusing on the special legal obligations and potential vicarious legal liabilities of the state and its licensed providers and their employees who are responsible for providing care and treatment, which includes protection from harm, sexual or otherwise.

Legal Background

First, what is a tort? It is a fairly simple concept. If living in a civilized society has a basic obligation of one citizen to another, it is that we all act with care toward each other so as not to needlessly cause a significant injury. And, if a person's carelessness or intentional action causes an injury to the person or property of another, then this is a "tort" and the perpetrator is liable to pay money damages to compensate for those injuries. And if the perpetrator is particularly careless, e.g., grossly, recklessly or wantonly careless or acted with intent and caused injury, then "punitive damages" might be awarded in addition to the compensatory damages.

In other words, a tort is the basic legal principle of society that says: if a fellow citizen acts carelessly—or worse, intentionally—and such violation of this civic duty causes a significant harm to another, then the actor should pay money to compensate that person for damage to his person, property or both. Even though money cannot replace many injuries or make the injured person whole again, it's the best solution which the law can provide.

In order to have the right to sue and collect such money damages in a court of law, the injured party (known as the "plaintiff") has to prove a tort against the responsible party (called the "defendant") for the injury. The plaintiff's presentation must prove by a preponderance of evidence (i.e., by the greater weight of the evidence or which party is more persuasive to the jury) that there was a:

1. **Societal Duty:** there was a violation of a recognized societal duty to act carefully (which duty could be found in statute, other written rule, or merely a social custom);
2. **Injury:** there was a significant injury (physical, emotional[3] or property) to the plaintiff; and,
3. **Proximate Cause:** the defendant(s) caused injury directly, indirectly or by a failure to take action where there was a recognized obligation to do so, thus allowing the injury to occur. This element is commonly understood to involve a determination over whether reasonable and prudent persons could have foreseen the injurious consequences of their act.[4]

The most well-known examples of a tort are car accidents, which often wind up in a courtroom with a plaintiff seeking money for property damage (to the car) or damages for personal injuries. A car accident plaintiff might have to prove that the defendant driver ran a red light (a statutory violation) or perhaps was driving at a legal, but imprudent speed during a snow storm (a custom or duty to drive safely under existing weather conditions), or was just not paying sufficient attention (i.e., was careless or negligent) to driving to avoid the accident.

The plaintiff would then prove the extent of his or her injuries (property and personal in terms of dollars demanded) and connect the injuries to the defendant by showing that they were foreseeable to a reasonable person as a natural consequence (proximate cause) of the defendant's carelessness.

One court expressly analogized negligent infliction of an STD to automobile accidents:

> [t]o be **strickened with disease** through another's negligence is in legal contemplation as it often is in seriousness of consequences, no different from **being struck with an automobile** through another's negligence. (emphasis in original)[5]

Sexual Torts

A recent court decision in New York has reaffirmed that a wrongful transmission of a sexually transmitted disease is a legitimate basis for a lawsuit demanding compensation from the persons responsible.[6] The particular social duties which might be recognized by courts in New York and in many, if not most, other states in the United States are:

- ☐ **Negligence:** that the defendant knew or should have known he was capable of infecting another, yet carelessly went ahead and did so;
- ☐ **Negligent Misrepresentation:** that the defendant carelessly either falsely expressed an infection free status, or carelessly omitted revealing his or her infection;
- ☐ **Fraudulent Misrepresentation/Deceit:** defendant intentionally deceived his or her sexual partner concerning a sexually transmissible disease;
- ☐ **Battery:** defendant knew of the possibility of infection and intentionally proceeded notwithstanding this knowledge;
- ☐ **Intentional Infliction of Emotional Distress:** defendant knew of his disease and of the emotional damage it would cause his sexual partner and intentionally committed the act;[7]
- ☐ **Violation of a Law, Regulation or Policy:** injury caused by a lack of adherence to written law and/or rules, especially violations of the criminal laws. For example, numerous states have laws that make the intentional transmission of a venereal disease a crime.[8]

A very recent decision by a New York State court illustrates the application of these priorities. It concerned a person who had homosexual relations with another, but did not disclose the fact that he had the human immunodeficient virus, the so-called HIV infection, which is believed to cause the disease of AIDS. The plaintiff, a homosexual man who had developed no symptoms of HIV/AIDS, nevertheless sued his employer, a bank, because a bank employee with AIDS had sex with him and because the bank fired him, allegedly for discriminatory reasons. The judge stated that since the plaintiff showed no sign of infection, there was no provable injury, but also opined:

> In my view, a cause of action may be stated against an individual who transmits HIV to another individual. Battery is a possible foundation. . . [n]egligence is a valid theory. . . A duty arises when a person engages in such a special relationship, a duty to use reasonable care not to transmit a sentence of death to his or her partner. This duty must exist outside and be separate from traditional husband/wife relation-

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> ships if the law is accurately to reflect the present mores of the land and if the state is to maintain the role of protector against needless death. Although the state ought to intrude into the bedroom only in extraordinary circumstances, there clearly is a great and overriding public interest in limiting the spread of this dreadful illness.[9]

Vicarious Liability

In terms of vicarious liability especially for persons who have caretaker duties and fail to carefully supervise and protect vulnerable people for whom they are responsible, legal duties might be imposed upon them as well.[10] The following are common examples, but are not the only possible legal theories that exist or might be created in the future:

- ☐ **Negligent supervision:** a custodian is careless regarding the recognized obligations to protect a person from sexual injury;
- ☐ **Professional malpractice:** where a professional, such as a psychiatrist, psychologist, physician, licensed social worker or program professional, is careless about following law, regulations or practices recognized and accepted in the respective professions and thereby causes or allows to be caused injury to another;
- ☐ Facilitation, participation or approval of the tortious conduct of another.

Legal Principles, Common Problems and Practical Solutions

While it is difficult to envision and impossible to cover in this article all the possible scenarios of tort liability for sexual behavior and the possibilities of vicarious liability, some general cases and principles can be discussed as being the more likely problems that might arise.

Capacity to Consent

The first question about sexual activity between persons with a mental disability that should arise for a provider, a professional such as a psychiatrist or psychologist, or another professional who would be considered to have a duty to protect against sexual harm, is whether or not such a potentially sexually active person is capable of consenting to sex. Capacity to consent, also known as legal competency, is what distinguishes appropriate sexual activity from a potential sexual crime or a civil tort of failure to protect a person from sexual harm.

While a person's competency can almost always be decided by a court of law, it can also legally be and is more frequently done by a qualified professional (e.g., a psychiatrist, psychologist, physician, etc.). Consent is commonly known to be required by law for major medical decisions.[11] Consent for sexual activities for persons with mental retardation is not only a matter of laws, but also is covered as a care and treatment issue by regulations of the state.[12]

With certain persons it might be difficult to determine competency to engage in sexual activities because that person is considered by professional judgment to be on the margin between being clearly competent and clearly not competent to consent to certain sexual activity. However, such cases are not novel or unique and resolution can be obtained from seeking other professional opinions in some cases through the regulatory process, or, in rarer cases, presenting the case to a court of law for a decision on competency.[13]

Permitting, facilitating, encouraging or failing to stop sexual activity with a person who, due to mental incapacity, can not give consent would potentially implicate the criminal laws against rape and sexual exploitation (endangering the welfare of an incompetent person), and certainly be actionable under the civil laws of torts if injury results.

Sexual Diseases

While a clear case can certainly be made for a person who knows he or she has a sexual disease, yet intentionally ignores that fact and goes ahead to have sexual relations with another anyway, basic tort law of negligence (i.e., carelessness) would apply even if the person did not know for sure whether he or she had a sexual disease. There might be legally valid grounds to claim that he or she should have known of such infection and the possibility of transmission by virtue of symptoms, certain lifestyle habits, such as previous promiscuous behavior, intravenous drug use or other risky conduct. Thus, the failure to be tested on a regular basis, or the failure to take adequate precautions, or the failure to warn the sexual partner, or other such omissions might well make that person responsible for any resulting injuries from an STD.

Additionally, the use of a condom will not necessarily be a simple "solution" or a reason to be careless regarding warning a sexual partner. A study by the famous sex researchers Masters and Johnson stated that: "to think that condom use is perfect, or even near perfect, in eliminating the risk of HIV transmission is foolishness of the highest order."[14]

For the professionals and licensed caretakers who have a duty to protect their clients from harm, not only the consent issue but also the issue of the methods of protection can be a source of possible liability. If a person is found competent to consent to sexual activity but is not provided with adequate education and training including methods of birth control and disease prevention, it might constitute a failure of adherence to professional or custodial standards if injury results.

Although it is beyond the scope of this article, it is worthy of mention that the U.S. Supreme Court has held that the state, and in most cases its licensees, owe a constitutional duty to provide proper nutrition, habitation, medical care and protection from harm. Thus, the analysis in this article might also have a constitutional law dimension as well as one in the civil law, which would mean among other things that a lawsuit could be brought in federal court as well as in the state court.[15]

Whether it is constitutional law or civil law, persons with mental disability who are in the care and custody of the state and its licensees and who are found to be competent to consent to sexual activity, should be offered education and training including adequate modes of protection from STDs. This should include periodic offers of testing for sexually transmissible disease if the person is known to be sexually active, especially with more than one persons or with persons who might be suspected of being in high risk groups, e.g., intravenous drug users.

One of the legal elements for liability, as noted above, is whether the resultant injury was reasonably foreseeable upon the exercise of reasonable ("professional" where applicable) care. For example, if a person with mental retardation is found to be capable of consent to sexual activity, has been given proper education about sex and methods of birth control and STD prevention, yet chooses to or fails to employ it properly thereby contracting an STD, there might not be any grounds to accuse caretaker of being negligent or careless.

But the mere fact that proper consent for the sexual activity exists, by itself, does not eliminate the possibility of these other liabilities based on a failure to educate, train, and otherwise protect. Court decisions have drawn a distinction between consenting to sexual activity per se and "consenting" to the risk of being infected with a fatal or debilitating sexual disease. These decisions reject the notion that consent to have sex can be a defense to the intentional or negligent infection with a venereal disease.[16]

Pregnancy

Of course, venereal disease isn't the only potential life-threatening condition resulting from sexual relations. There have also been cases dealing with ectopic pregnancies, where one partner asserted that he was sexually sterile in order to get the other to consent to sexual relations.[17] The courts have refused to recognize that an unwanted pregnancy is a legally valid "injury," reasoning that "life" is a positive event not an injurious one. However, there are legal proceedings which can compel a putative father to make money payments to support his child.

However, a recent judicial decision by the Supreme Court of Indiana ruled that there were alternate grounds to award damages to a person with retardation who became pregnant by rape while in the facility's care. The rape of this resident with retardation occurred in a total-care nursing home. The court ruled that she would have a cause of action for the nursing home's negligent failure to protect her and to diagnose and properly treat the pregnancy. The rationale of the court was as follows:

> Clearly, the nursing home owed a duty to the mother, a total care resident, as an invitee. This duty was to exercise reasonable care for her protection. In addition, because the nursing home was aware of the disabilities and infirmities which rendered the mother unable to care for herself, it had a duty analogous to that of a common carrier **to provide protection and care**. . . . Given the extreme dependence of the mother on the nursing home for her protection and care, the great degree of control available to the nursing home and the discharge of its obligations, we have no hesitation in declaring that its duty to the mother also extended to her unborn child. A breach of duty proximately resulting in injury to the child would support a cause of actions on behalf of the child.[18]

(emphasis added).

Punitive Damages for Sexual Injuries

As so-called "compensatory damages" are awarded for proven physical, emotional or property injuries to the degree they can be evaluated in terms of dollars, "punitive damages" are generally reserved for exceptionally egregious cases which contain elements of malice, fraud, oppression, insult, wantonness or other aggravated circumstances which either affect the public interest or which shock the conscience of the court. They are meant to provide a deterrent to such behavior, punish the perpetrator and to provide the plaintiff with an extra measure of money beyond that meant for compensation for actual proven injuries.

Punitive damages have been awarded in sexual abuse situations.[19] There is too little space to adequately do more than mention this possibility for civil lawsuits on sexual activities and to note that such damages are usually only awarded for acts that are more than careless, i.e., which can be said to be grossly negligent or worse.

Conclusion

Licensees, professionals and their agents as caretakers of persons with mental disabilities have legal obligations to protect them from harm, including sexual harm. There is also the obligation to nurture their abilities to permit them to lead a fulfilling life, including participating in sexual activities where they are able to consent.

Ironically, while the law will hold such persons responsible pursuant to the above principles, the law also uses such professionals to define the circumstance of appropriateness, of carelessness and of the other factors which determine whether the actions were the causal basis for injury or whether there is no culpability for consequent injury.

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Plain Talk About Sex and Mental Retardation

by Clarence J. Sundram

Clarence J. Sundram

The AIDS quilt project is making its way across the nation. In every community, its presence calls attention to the lives that have been cut off in early bloom by the dreaded and presently incurable disease. The fatal consequence of infection with HIV has prompted frantic efforts by researchers, public health officials and educators to prevent its spread. A key tool in the battle is information — about the nature of the risks, the methods of infection, and measures to guard against and reduce risks.

A brochure about the AIDS quilt's forthcoming display in Albany came across my desk at the same time as I was following a complaint made to the Commission about a residential facility where the complainant's mildly mentally retarded sister had contracted AIDS through sexual activity.[1] "Why aren't we doing more to protect her sister and others like her?" she seemed to be asking. "How many mentally retarded people have died of AIDS?" I wondered. "Are there memorials to any of them on the quilt? What *are* we doing to protect them from unnecessary risks?"

The sexuality of people with mental retardation in residential facilities is a reality to practically everyone who works in this field, yet many seem to have found it more convenient to turn a blind eye to their sexual conduct because it raises complex legal, social, moral, ethical, religious, health care and even political questions. They have been content to pretend it doesn't happen[2] or, if it does, to hope fervently that they aren't faced with a pregnancy or a sexually transmitted disease that forces acknowledgment of sexual conduct, consideration of the consequences for the individuals and the program involved, and their own ambivalence in dealing with the questions raised.

Sexual Abuse and Exploitation

In our work at the Commission, we are exposed more than most people to what Erving Goffman referred to as the "underlife" of institutions and other residential programs. The growing volume of cases and complaints we receive involving the sexual abuse and exploitation of people who are mentally retarded forces us to confront the tattered fabric of the safety net that is supposed to protect vulnerable people from harm. And what we have learned from these cases frightens us enough to sound the alarm, particularly as the gravity of the risks of sexual conduct has risen dramatically with the spread of HIV infection.

While there is some support in the literature for the proposition that people with developmental disabilities are at greater risk of sexual abuse and exploitation at the hands of staff, caregivers and family members than the general population,[3] there is much less written about their abuse and exploitation by other program participants. It is this area that seems to present the greatest likelihood of a failure to protect them from harm and that is the subject of this discussion. This article does not deal with "low risk" sexual activities like kissing, hugging and fondling; rather, it addresses sexual activities that pose a risk of pregnancy, transmission of disease, or infliction of injury to one of the participants.

In reviewing and investigating serious incidents, the Commission has found:

- ❑ Forcible rapes and sodomies of mentally retarded men and women by other residents of facilities that often go unreported, uninvestigated, and, therefore, the underlying conditions remain ripe for recurrences.[4]
- ❑ Sexual intercourse and sodomy involving severely and profoundly mentally retarded residents of facilities, whose capacity to consent to sexual conduct is highly questionable, going unreported, uninvestigated and unaddressed in program planning.[5]
- ❑ Residents who have been severely physically injured, have contracted sexually transmitted diseases or have become pregnant.
- ❑ Residents who have had sexual relationships with others whom staff have known to be HIV positive, and who have often either not understood the nature of the risks or not had a clear understanding of how to protect themselves.[6]

Protection From Harm

The Commission has attempted to understand why facilities failed to report these incidents, adequately investigate them or take what appear to us to be reasonable protective and preventive measures or to equip the residents themselves to take such measures despite a clear regulation defining sexual intercourse and sodomy between residents as "sexual abuse" unless both partners are consenting adults, and requiring such reports, investigations, and the implementation of corrective actions.[7]

Flawed Reasoning

Underlying the inaction is a variety of flawed rationales, sometimes clearly stated but often unarticulated:

- ❑ *Sexual activity is private for other adults and so should it be for the adult who is mentally retarded as an aspect of normalization. **Flaw:*** **Sexual activity is a matter of privacy for consenting adults. If there is no consent or if one of the parties lacks the capacity to consent, the conduct may be criminal and subject to criminal prosecution. It may also be a violation of civil law and thus a matter of serious public interest. Both law and regulation require the reporting and investigation of such incidents.**[8]
- ❑ *Mentally retarded adults have the same right to engage in sexual activity as other adults and programs have the right to rely completely on the legal presumption that all adults are competent unless there has been a judicial declaration to the contrary. **Flaw: Competent*** **mentally retarded adults have such rights but not all such persons are competent; relying on a presumption alone to establish competence is an invitation to disaster for the individual and to liability for the professional**[9] **(see discussion below).**
- ❑ *Yes, there are risks inherent in sexual activity but mentally retarded adults should not be denied the "dignity of risk." **Flaw:*** **There is no dignity in exposure to risks one does not comprehend and against which one is not able to protect oneself.**

Lack of Policy Guidance

In virtually every program where the Commission has found the types of problems described above, we have also found a lack of clear policy guidance for staff in dealing with the sexual aspects of the lives of the residents. Many agencies have no policies at all, or they are ambiguous, or they hide behind legal fictions like the presumption of competence. Some agencies have written or unwritten policies that ban sexual activity entirely and a culture to look the other way when it occurs.

The repetitive nature of the problems we have been witnessing in a multitude of programs led the Commission to publish a report on one facility [10] calling for clearer guidance for programs and staff in dealing with sexuality and sexual behavior of persons who are mentally retarded. The OMRDD responded by issuing draft guidelines for state-operated and state-licensed programs.[11] The reactions to the OMRDD guidelines from parents, providers, self-advocates and other advocates has been instructive, at least in part because they reveal widely divergent views on what exactly is a providers' obligation in this sensitive area, on the rights of people who are mentally retarded to participate in sexual activity, as well as a significant degree of confusion about a fairly clear legal obligation of a provider to protect vulnerable people.

Confronting the Issues

The message of this article to program operators is fairly simple: **You can't hide behind a wall of silence on this issue!** You have to deal with the reality of sexuality of people who are mentally retarded, and confront your dual obligation to help them lead as normal adult lives as possible, while protecting from harm those whose decision-making incapacity in various areas of their lives, including sexuality, leaves them vulnerable to being abused and exploited. Staff need clear guidance and training on how to deal with the practical problems they are bound to encounter in dealing with the sexual behavior of the people they serve.

What should a program operator do? The first obligation is to develop a good sense of the strengths and needs of the person for whom you are responsible. Clinicians have a clear professional duty to conduct an adequate assessment of the functioning abilities and training needs of the persons entrusted to their care, consistent with the standards of their profession. (How else can they develop the *individualized* habilitation plans?) Thus they have a legal duty to know or to find out about a person's abilities and needs, and cannot avail themselves of "presumptions" which the law uses to fill voids when there is an absence of knowledge. Few would argue that it is reasonable or prudent to permit a severely or profoundly retarded adult to cross a busy highway based on nothing more than a "presumption" of ability to negotiate traffic. It makes as little sense to presume competence of such a person to make decisions about sexual behavior where the risks may be as great, and even less sense if you have reason to know that the person needs help with many other types of decisions.

Evaluating Competence

Part of the task is to evaluate competence to make decisions about sexual behavior where this is in question. What does this require? Simply stated, it requires ascertaining whether the individual has adequate:

a) **knowledge** about the nature of the sexual activity, about the attendant benefits and risks (e.g. pregnancy, disease, etc.) and about methods of reducing or eliminating the risks;

b) **intelligence** to evaluate the knowledge and make a decision consistent with personal values and beliefs; and

c) **voluntariness** or an understanding that there is a choice of whether or not to engage in the behavior in question, and an ability to make the choice—i.e. to feel free to say "yes" or "no".

This last point is particularly important. There has been a long history of teaching people who are mentally retard-

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Plain Talk

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ed to be compliant. It is a trait upon which great value has been placed. Ironically, the success in inculcating this value of compliance is also likely to diminish their ability and willingness to say "no" to a sexual encounter even when they do not want to participate.

The Commission often reviews cases of people in the severe and profound range of mental retardation, who are found engaged in sexual activity, and whose clinicians freely admit that they lack any understanding of the nature or consequences of their actions. In some of these cases, one of the participants may have had the ability to scream or push away an unwanted sexual overture, but did not do so although they later told a trusted adult that they did not want to participate but were afraid or could not refuse. Yet, these cases have been treated as if they involved competent consenting adults.[12]

It is important to honestly confront the reality that **some** people who are mentally retarded are going to be found incompetent to consent to sexual activity, and programs will have a concomitant duty to protect them from being abused and exploited by others who would engage them in such activity. It is likely that many, if not most, people in the higher ranges of mental retardation will be found competent to consent, or could be made competent, with education and training. It is also likely that many, if not most, people in the lowest ranges of mental retardation may not be able to develop the requisite knowledge and understanding to be found competent to consent.

Important Safeguard

The clinical evaluation of competence to consent is an important safeguard for the mentally retarded person. It should help clearly identify sexuality education and training needs of such persons to enable them to make decisions and exercise rights for which they have the competence. It should also identify the need for protection from abuse and exploitation of those who are found not to be competent. Such clinical evaluations are in the best interest of the clinicians and the programs as well. Both the civil and criminal law give great deference to sound clinical judgment.[13] A clinical determination that is made following reasonable efforts to gather the relevant facts, that applies reasonable criteria to determine competence (such as those enunciated earlier) and that falls within the broad range of professional opinion, is what the law requires and usually will not be overturned by a court even if it turns out to have been wrong. But a failure to exercise professional judgment will almost certainly result in a finding of liability if it results in harm to a person for whom the professional was responsible.

Conclusion

Developing clear policies to guide staff, providing staff training, arranging for thorough individualized clinical evaluations of competency, providing program participants with the education and training they need in the area of sexuality, including self-protection, and arranging for adequate supervision to protect from harm those who are unable to protect themselves — all these are essential obligations a provider agency undertakes. Even if all these measures are diligently implemented, incidents are likely to occur. Programs must develop a mindset that values honestly confronting the facts, seeing the incident as an opportunity for critical self-examination, or for seeking outside assistance, and for learning from such experiences how they can prevent recurrences and better protect the people they serve from harm.

All of this may sound like a daunting challenge for provider agencies. What sustains our optimism is the Commission's day to day work in monitoring programs that serve people who are mentally retarded. For all the problems we see, we also regularly encounter agencies staffed by caring and concerned professional and direct care staff, and guided by strong leaders who communicate a clear commitment to promoting regular lives and protection from harm. They see these dual tasks as part of the same obligation they undertook in deciding to provide services and supports to the people they serve and in doing so, they routinely meet all of these expectations with grace and sensitivity.

Endnotes

[1] See the article by B.J. Chura, "Protection From Harm: AIDS in Residential Facilities," p. 1, this issue.

[2] See Sandra Cole, who wrote she has titled many of her presentations to professionals "Don't Tell Me What I Don't Want to Know," in the Foreword to *Disability, Sexuality and Abuse: An Annotated Bibliography*, by Sobsey, Gray, Wells, Pyper and Reimer-Heck, Baltimore: Paul H. Brookes, 1991 [referenced in the article, "Sexuality and People with Developmental Disabilities: A Glance at Some of the Literature," page 6, this issue].

[3] Winifred Kempton and Emily Kahn, "Sexuality and People with Intellectual Disabilities: A Historical Perspective," in *Sexuality and Disability*, Vol. 9, Summer 1991, p. 106.

[4] See the Commission report, *Sexuality and Developmental Disabilities: An Investigation of Sexual Incidents a Bernard Fineson Developmental Center*, November 1991.

[5] Id.

[6] See note 1.

[7] 14 NYCRR Part 624(2)(b)(2).

[8] NY Mental Hygiene Law, §16.13(b); 14 NYCRR Part 624.

[9] See Counsel's Corner, this issue, pp. 2-3.

[10] See note 4

[11] The draft guidelines were published in *Quality of Care,* Nov-Dec 1991, pp. 4-6.

[12] In New York, the state's highest court, in *People v. Easley,* 42 NY 2d 50 (1977) articulated an additional requirement for the "knowledge" component of the competence test. It ruled that the individual, to be found competent to consent to sexual intercourse, also must have an understanding of the "moral quality" of the behavior in question and how it is regarded in the framework of societal taboos. The court has made it clear that the individuals do not have to conform their behavior to such notions of morality, simply that they understand the moral dimensions of their behavior.

Other states, like New Jersey (*State of New Jersey v. Olivio,* 123 N.J. 550, 1991), have no such requirement and the statutes and court decisions instead focus simply on the voluntariness of the decision, — could the person say "no"— even if the person has less than complete understanding of the consequences of his or her action.

While there has been a great deal of debate over the wisdom of the court decision in *Easley* in response to the OMRDD draft guidelines, and particularly over the high level of intellectual functioning that a "morality test" requires, in the approximately 600 cases the Commission reviews each year involving sexual activity and people with mental disabilities, the "morality test" has *never* surfaced as a factor. We have yet to encounter a case of a mentally retarded person who knows the nature of the conduct, understands the risks and benefits, is able to and does make a voluntary decision to engage in sexual activity but whose competence to consent is an issue simply because of the additional "morality test" under New York law.

On the other hand, and ironically, as this article is being written, there is ongoing in Glen Ridge, New Jersey a criminal prosecution of four members of a high school football team for sexual assault upon a 17-year-old, mildly mentally retarded student. The thesis of the prosecution is that the victim, who has an I.Q. of 64, did not have the ability to consent although she voluntarily participated in the sexual activity. Much of the evidence the prosecution has introduced in this case is designed to demonstrate the victim's strong desire to please others and to comply with their wishes even to the extent of permitting degrading sexual acts to be performed on her; in short, the prosecution contends, she was unable to say "no."

[13] *Youngberg v. Romeo,* 475 U.S. 307 (1982)

Suggested Policies on AIDS

As it becomes increasingly clear that a cure for AIDS is not imminent and that people with mental disabilities will not be spared its ravages, agencies which care for persons with mental disabilities must enact policies and procedures which both safeguard the liberties of residents and ensure their protection from harm. Recognizing that this is no easy task, the Commission suggests that each agency consider the following first steps:

☐ Develop a clear policy statement, consistent with current law and regulations, regarding sexual activity for persons in its charge which both safeguards the liberties of residents and ensures their protection from harm. This policy should include criteria for determining if a person has the capacity to consent to sexual activity, circumstances under which such determinations should be made, and assurances that the determinations reflect professional standards of care and treatment;

☐ Provide sufficient staff training to all levels of staff to enable them to implement the sexuality policy. Provide training on universal precautions for all staff;

☐ Ensure that each resident is provided initial and ongoing instruction on sexuality, relationships, self-protection and other related issues at a level appropriate to his/her present understanding. Provide special or individualized counselling for individuals who engage in high-risk behaviors;

☐ Incorporate appropriate measures, including but not limited to training, counseling and supervision, and offers of appropriate testing and medical care into the program plans of persons who engage in "at risk" behaviors and for those who are particularly vulnerable and unable to protect themselves;

☐ Secure informed consent for HIV testing in accordance with NYS Public Health Law, Article 27-F and procure such testing annually (preferably at the time of the resident's annual physical) for all persons who are at risk of contracting the virus in order to ensure early medical intervention and the protection of sexual partners, if that is an issue.

While the law and regulations governing the care and treatment of persons with mental disabilities are moving toward an increasing right of personal privacy, including sexuality, this development must be synthesized with the general obligation of care and treatment which essentially means at least protection from harm in addition to whatever amelioration of the disability is possible for a given individual.

Sexuality and People with Developmental Disabilities: A Glance at Some of the Literature

by Marcus Gigliotti

In the midst of the discussion on sexuality and people with developmental disabilities, a number of issues, many of them conflicting, have been raised. I decided to attempt a literature search to see what is being written on the subject. After several trips to the library plus a few computer searches, I discovered that many people, particularly in recent years, have addressed the issues from a variety of perspectives. Within the limited context of a newsletter article, rather than attempt to present a summary of all the literature I found on the subject, my goal will be to present a "glance" at some of the literature which I believe will be of special interest to our readers. Readers, as always, are encouraged to respond and send comments and other suggestions.

The Context, The Issues

First of all, a listing of some of the difficult issues:

- Right to protection from harm vs. right to sexual expression
- Exploitation, vulnerability vs. "dignity with risk"
- A cohesive, unified, coherent sexuality policy, vs. "respecting differences"
- AIDS and STDs
- Confidentiality laws and protection from harm
- Assessing individual capacity for informed consent
- Shocking rates of sexual abuse of children and youth with disabilities
- Potential liability of service providers for not protecting service clients from abuse/infection
- The gap between acknowledgment of clients' rights to sexual expression and preparation of clients to express themselves safely and responsibly
- The ability of clients to make judgments necessary to choose whether to abstain from sex or to practice safer sex
- The difference and challenge in educating about sexuality in a human dimension vs. "sex" as a skill to be learned similar to eating
- Establishing goals, guidelines, curricula, values, in sexual education
- Effective evaluation of learner outcomes
- Parent, family, guardian interests, beliefs and rights
- Coping with illness, death, and dying as a developmentally disabled person

One of the best ways to get started and oriented in the literature on these complex issues is to find a history—where have we come from? I found the article "Sexuality and People with Intellectual Disabilities: A Historical Perspective," by Winifred Kempton and Emily Kahn, in the journal *Sexuality and Disability,* vol 9, Summer 1991, pp. 93-111, particularly helpful. The article traces the attitudes at the beginning of our country, through the eugenics movement of 1880-1940, the civil rights movement and the "sexual revolution" years, the move toward normalization and deinstitutionalization, and the AIDS epidemic, which the authors cite as providing new impetus for improving education and training in this emerging field.

This journal, *Sexuality and Disability,* was "revitalized" in 1989 to treat issues related to sexuality and people with all types of disabilities, not merely physical. The summer 1991 issue is a special "state-of-the-art issue on the sexual issues of people with mental retardation/developmental disability," [from the preface by Stanley Ducharme, Ph.D., editor] coordinated by Pamela Boyle of the Coalition on Sexuality and Disability in New York City. She notes in the preface: "In these times of concern related to AIDS and other STDs, undesired pregnancy, and shocking rates of sexual abuse of children and youth with disabilities, professionals are acknowledging that it is no longer a choice whether to provide sexuality-related services to persons with developmental disabilities. It is a necessity." Besides the historical perspective article, there is an article on the need for guidelines for providing sexuality-related services to severely and profoundly retarded individuals; a piece on dealing with parents; one on harmonizing the right to sexual expression and the right to protection from harm [by the Commission's Counsel, Paul F. Stavis]; another on the "Circles Programs," educational programs by clinicians, teachers, paraprofessionals, and nonprofessionals to teach people with disabilities the adaptive skills needed for healthy, self-affirming, social/sexual development; a case analysis on counseling to a man with severe cerebral palsy; and the YAI AIDS prevention education program.

These are the types of articles which can provide a context for professionals and parents who are now beginning to engage in lively dialogues on the many questions related to the subject.

Harsh Realities: Abuse, AIDS

In facing the sad facts of abuse and spread of AIDS, for starters we can cite the historical article in *Sexuality and Disability* mentioned above: "Statistics vary, but they all indicate that from 80 to 95% of persons with disabilities are victimized sometime in their lives—many more than the general population—with over 90% of the perpetrators in caregiving positions"[p 106].

A helpful literature tool on the harsh realities of sexual abuse and people with disabilities is *Disability, Sexuality, and Abuse: An Annotated Bibliography,* by Dick Sobsey, R.N., Ed.D., Sharmaine Gray, Don Wells, Diane Pyper, and Beth Reimer-Heck, LL.B., published by Paul H. Brookes Publishing Co. in Baltimore, 1991. This book attempts to document all the critical work accomplished to the date of publication (1123 titles are abstracted) in the "challenging and disconcerting area of sexual exploitation, abuse, neglect, and vulnerability among persons with disabilities" [From the foreword]. Sandra Cole, who wrote the foreword, says she has titled many of her own presentations to professionals since the late 1980s "Don't Tell Me What I Don't Want to Know." Many of these studies indicate the statistics are higher for sexual abuse among persons with disabilities than they are for the general public. Caregivers, acquaintances, and family members are generally the offenders.

Sandra Cole says she has titled many of her own presentations to professionals since the late 1980s "Don't Tell Me What I Don't Want to Know."

This annotated bibliography contains citations of articles and publications that focus on families, agencies, institutions, facilities, hospitals, and those who care for persons with disabilities. The purpose of the bibliography is to "encourage helping professionals in both public and private sectors to speak up, to intervene, and to be active in developing and exchanging new information regarding material, ideas, and methods for teaching and prevention. The results of continuing this difficult work will yield decreased vulnerability and prevalence of sexual exploitation of persons with disabilities and increased prevention, personal safety, human services, and self-esteem for person with disabilities and for professionals who work with them."

On the same topic of protection of vulnerable persons, Suzanne M. Sgroi, M.D., is a noted writer, teacher, and consultant on the subject. One volume I had a chance to peruse which she edited and contributed to is *Vulnerable Populations: Sexual Abuse Treatment for Children, Adult Survivors, Offenders, and Persons with Mental Retardation,* published by Lexington Books, 1989. I found her chapters on sexual abuse avoidance training for adults with mental retardation (including a detailed curriculum for adults with severe, moderate, and mild retardation), and evaluation and treatment of sexual offense behavior in persons with mental retardation particularly realistic, sensitive, and effective.

A recently published work raises the various complex issues—medical, social, legal, and educational—associated with HIV infection and people with developmental disabilities: Allen C. Crocker, Herbert J. Cohen, & Theodore A. Kastner, Eds., *HIV Infection and Developmental Disabilities—A Resource for Service Providers,* Baltimore: Paul H. Brookes Publishing Co., 1992. The goal of the book is "to speak to primary service providers, public planners, families, and students about the meaningful link between developmental disabilities and the presence of HIV infection....We also hope to ensure that HIV infection can be prevented in persons with disabilities, and if accidental infection occurs that effective programs can be maintained." There are three main sections. Part I focuses on children with congenital HIV infection, emphasizing epidemiology, medical treatment, the circumstances of families, and what happens when the child or family ventures into the developmental services and child welfare systems. Part II raises the issues related to youths and adults with developmental disabilities and HIV infection. Here the challenges in providing educational programs for people with developmental disabilities—and evaluating these programs—are discussed. HIV infection, sexual abuse, and criminality in the context of people with developmental disabilities are addressed. The urgent need of developing a comprehensive sexuality policy with procedures and standards is emphasized. Policy considerations are the entire focus of Part III. A legal overview is provided in a national protection and advocacy context. Also discussed in this part are the importance of developing policy and procedures related to confidentiality, the liability of service providers, a review of a survey of state guidelines and policies, the financing of developmental services, training caregivers in transitional homes, a summary of policy recommendations from a national conference on the subject of developmental disabilities and HIV infection, discrimination and integration as they affect public opinion, the link between intravenous drug abuse in mothers and HIV infection of children, and prevention efforts among women at high risk of HIV infection or already infected with HIV.

This book, intended as a current "state-of-the-art," can at least be called a "state-of-the-discussion." It does highlight the complexity, and even confusion, in some of the issues raised. It may prove to be more appealing to professionals and researchers than to on-line staff, care providers, and family members.

The Positive Side: Sexuality Personalized

One of the refreshing authors to read on the topic of sexuality and people with developmental disabilities is Dave Hingsburger. Direct care staff, families, and advocates will find his writing inviting, thought-provoking, and even inspiring. One of his books I read from cover to

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Sexuality Literature

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cover is: *I Contact—Sexuality and People with Developmental Disabilities,* Mountville, PA: VIDA Publishing, PO Box 597, Mountville, Pa. 17554, 1990. Here he speaks of a common mistake in sexual education programs and management of people with developmental disabilities: "The reduction of developmentally handicapped people's needs to biological urges is a tempting proposition. By taking sexuality out of the context of human interaction and human interchange, sex becomes simple behavior. Simple behaviors can be programmed away. The fires of passion are dealt with by the fire extinguisher of programming. Behaviors can be programmed; loving need never be discussed." He says some tend to treat clients merely as "behavior-emitting entities...As such it is important to keep in mind the fundamental belief that you are providing *human* services to *human* beings." This common error in sex education can lead to decisions that make programming inhumane. "Every one of us would feel offended if our own personal loving relationships were seen from only a genital perspective. Each of us would define our relationships by the quality of time spent together. When talking about our partners, we talk about the strength of the caring rather than the frequency of intercourse. We define our relationship in terms of support rather than in terms of sex. Each of us would resist the implicit message that our relationship was valued solely by activity below the belt..." His book goes on to discuss the ability of people with developmental disabilities to love, the development of a healthy self-concept, the meaning and cultivation of privacy, and other factors in the formation of a healthy sexuality.

This mistake and approach was pointed out some twenty years ago by R.B. Edgarton ("Anthropology and Mental Retardation," in L. Nader and T. Maretzki, eds., *Cultural Illness and Health*, Washington: American Anthropological Assoc., 1973) where he stated that the "typical publications on 'sex for the retarded' deal with the image of genital sex, which is an absurdly narrow definition." So also R. Meyers (*Like Normal People,* NY: McGraw-Hill, 1978): "Their interest was affection, something few people were willing to grant them." [In 1979 an award-winning and acclaimed television presentation based on this book was aired by ABC].

The Difficult Task, Yet Urgent Need: Guidance and Policies

One constant theme in the current literature I surveyed, including a computer search of some 213 abstracted pieces, is the importance and urgency of establishing written policies and guidelines. Some of the reasons: the potential liability of service providers, presenting the criteria used for the assessment of capacity to consent, maintaining confidentiality procedures, detailing procedures for reporting and investigating sexual abuse, establishing educational policies—within a consistent framework for the agencies. The need for coherent institutional and community policies, practices, and attitudes was indicated twenty years ago at a national conference sponsored by the National Institute of Child Health and Human Development on November 7-10, 1971 in Hot Springs, Arkansas (see, Felix F. de la Cruz, Gerald D. LaVeck, eds., *Human Sexuality and the Mentally Retarded*, NY: Brunner/Mazel, 1973). A good description of the process used in one community agency (Morris Unit of the New Jersey ARC) for the establishment of guidelines for serving people with developmental disabilities living in the community and infected with HIV is presented in *Mental Retardation*, Vol. 28 (June 1990), 139-145. The conclusion to this piece is a fitting end to our "glance" at the literature:

> We are in the midst of the epidemic spread of HIV. We must begin to develop policy that reflects our philosophical principles, current scientific information, and the practical and ethical needs of serving people with developmental disabilities. We must look beyond our individual fears and consider the reality of the transmission of HIV and the remote risk we undertake in providing services. Most important, we must exercise responsible leadership in deciding how we will meet these challenges.

Amen!

AIDS in Residential Facilities

Continued from Page 1

sexual relations with the residents who were HIV+, securing consent for testing.

With joint direction from the Commission and the OMRDD, additional issues were identified which required immediate attention:

- ☐ Sex education needed to be expanded, revised, and formalized. Although formal sex education was being provided to some residents, there was not an accountable process to assure that other residents in need were getting the instruction they needed.
- ☐ Although other sexually active residents were supposed to participate in informal group discussions, their attendance at these sessions was not verified, there was no formal curriculum to cover nor any measures to insure that participants understood critical issues. Agreement was reached with the agency that all residents would receive appropriate sex education, including training in "saying no."
- ☐ Substantive revisions were necessary in the treatment plans of some residents to address sexual behaviors, particularly persons with multiple partners and those who did not use safer sex practices. Assessments of the self-protection skills of other residents and of their need for increased supervision were necessary.

With assurances from the OMRDD of support and technical assistance, the facility began to implement these corrective actions. As HIV tests returned negative, the administration began to give attention to additional systemic measures necessary to minimize risks to residents and to ensure the protection of vulnerable persons in the future.

The facility agreed to ensure that all residents who had tested negative would be retested in six months so that they and their families could rest with a degree of certainty that they had not contracted the virus. The facility also agreed to make a good-faith effort to secure permission for HIV testing each year, at the time of their annual physical, from those persons displaying at-risk behaviors or from surrogate decision-makers as appropriate.

It is clear that this agency has a great deal of work to do to ensure that each person on the campus understands to the best of his/her ability the risks and benefits of sexual activity with a partner and that persons who are unable to consent to such activity are protected from harm. The Commission and the OMRDD have both pledged their support. The Commission will continue to monitor the facility to ensure that the corrective actions have all been implemented, are effective and to assess if further measures are necessary.

Unfortunately, as the Commission is aware from monitoring serious incidents occurring in residential facilities, this situation is not unique to this agency. Indeed, one of the former residents of this facility now lives in a developmental center where all of the persons on his unit had been determined not to have capacity to consent to sexual activity but where, according to staff, residents are often sexually active with multiple partners.

Although sexual activity between residents who do not have capacity to consent is considered "sexual abuse" and thus a reportable incident under OMRDD regulations (14 NYCRR §624.4(2)), at this facility such incidents were not being reported or investigated. The hazards of such facility practices were recently discussed in a Commission investigation report, *Sexuality and Developmental Disabilities: An Investigation of Sexual Incidents at Bernard Fineson Developmental Center.*

Whether a program errs by doing no capacity assessments, presuming all residents are competent, or conversely determines that even very capable persons lack capacity to consent, it opens itself to liability and exposes its residents to jeopardy. This experience and many others demonstrate all too vividly the need for programs to deal thoughtfully and consistently with sexuality issues based on articulated agency values which acknowledge both the responsibility to ensure the rights of individuals and to protect those persons who cannot protect themselves.

It is, quite simply, a matter of life and death in all too many cases.

One Opinion

by Betty Jane Chura

The premise that we can responsibly discharge our obligations to persons with developmental disabilities when we teach them the mechanics of sex and safer sex practices but do not teach them about love and special relationships is discriminatory.

In teaching "typical" children about sex, we do not limit ourselves to anatomy and physiology. Rather, we talk over the length of their childhood about respect for themselves and others, feelings, intimacy, commitment, relationship, hurt and disappointment, and myriad other aspects of the moral and psychological contexts of sex between two people.

Why is it somehow alright to give persons with developmental disabilities less? Surely it is not because they do not have these feelings nor is it because we do not know how to teach these broader concepts. Is it perhaps the unconscious determination that "half the loaf" is good enough for them?

The Commission invites your comments and responses to this "One Opinion." Please direct them to:

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The Failed Promise of A Residential Alternative: A Case Study of Deceit

by Bill Combes

“Aging Out” is apt shorthand which portends the grim eventuality faced by thousands of individuals whose legal entitlement to free and appropriate educational services, including a residential placement if needed, ends with their twenty-first birthday. All too often, if a safe home and a nurturing environment is what is needed, young adults with developmental disabilities have little to celebrate at that milestone. Present social policy is less kind to them the day after: the intensive programming that formerly assisted them through Individualized Treatment Plans (ITPs) ceases abruptly; good places to live, for people no less disabled on the first day of their twenty-second year, become scarce.

The paucity of adult residential programs in New York are, for some, a business opportunity. This story is the account of one operator, one residence, and the 104 adults who lived there in the bucolic setting of Rhinebeck—until the State, in a cooperative venture involving several agencies, and spurred by the concerns of clients, families, and advocates, moved to close it down.

Woodcrest Manor Home for Adults actively recruited adults with developmental disabilities to fill its many rooms. To visitors, the surrounding grounds seemed welcoming and lent the appearance of a caring environment. Those who visited the facility rarely were allowed to venture beyond the very well-appointed sitting room. However, beyond the main door existed a starkly different reality: environmental neglect, poor-to-nonexistent supervision, abuse and fear. One resident reported that he could not sleep because of the yelling, noise and threats that assaulted him throughout the nights.

Citation History

The history of this facility was replete with citations for deficiencies issued by the State Department of Social Services (DSS). In fact, Woodcrest had a troubled DSS inspection history dating back to at least 1981. For example:

- The home had not received a “compliance” or “substantial compliance” rating on a DSS annual inspection report since 1981.
- The DSS record on Woodcrest cited an unusual number of very serious complaints against the home. Since 1981 a total of 59 complaints had been filed by outside parties as varied as the Secretary of State’s Office, the local fuel company, doctors at local hospitals, day treatment providers, family members, staff of the home, and residents.
- The operator of the home suffered only a single $2,850 enforcement fine over a ten-year period (1981-1991). Several other enforcement actions were initiated, including an application for receivership in 1988 and an unsuccessful action in 1989 to revoke the operator’s license; these failed.

How They Came to Live There

The Office of Mental Retardation and Developmental Disabilities (OMRDD) played a direct role in placing many of the mentally retarded residents in Woodcrest. Some were former residents of Wassaic Developmental Center; others were moved to Woodcrest, under Wassaic’s supervision, from the Rhinebeck Country School upon its closure in the late 1970’s.

Early on, Wassaic officials began to encounter problems with the operator of the Woodcrest Home, who wanted to discontinue the residents’ “conditional release” status and stop contact and services by Wassaic staff. Reportedly, OMRDD officials say a court order settled this dispute by authorizing limited Wassaic staff contact with Woodcrest residents. From discussions with OMRDD officials, as of the early 1980’s Wassaic staff began to have significant reservations about the quality of care at Woodcrest and the “good intentions” of its operator. Wassaic stopped referring persons with developmental disabilities to the home, but Woodcrest continued to receive admissions from other sources. Thus, for example, developmentally disabled offenders were referred by local probation departments and entered the home.

Commission Involvement

The Commission on Quality of Care became aware of this facility after its Protection and Advocacy program office in Poughkeepsie, Mid-Hudson Legal Services (MHLS), was contacted by a parent who complained that her son experienced significant weight loss at Woodcrest and that he was not receiving adequate dental care. When Commission and MHLS staff visited Woodcrest, darker realities about life at the home began to emerge. There wasn’t a sign of supervision, despite the approximately 30 individuals with moderate retardation idling about the facility. And, despite the carefully guided nature of the tour provided by the operator, the physical plant observed was plainly substandard: the walk-through revealed torn carpeting, poorly lit hallways and an almost maze-like configuration of living spaces which could easily disorient residents in an emergency. Further, a record review indicated that many residents had left a much higher level of care before arriving at Woodcrest. In many instances their placement was arranged by a contract agency specializing in case management services to individuals “aging out” of children’s residential facilities. The transition, for many of these people, ushered in harsh living conditions they were ill-equipped to confront.

With this first visit began an odyssey of litigation in State and Federal tribunals and, ultimately, an unprecedented CQC, OMRDD, and DSS coordinated effort aimed at protecting the welfare of the residents.

The move has benefited the young man in question and he may quite possibly experience a re-unification with his family, thanks to those who earnestly believed that the system could work—even if it had to be pushed.

More than simple agency resolve was needed, however. In order for DSS to prove that those residents were not suited for life in the adult home, expert testimony would be needed. That was left to OMRDD clinical staff, who heretofore had been barred from Woodcrest, which was licensed by DSS, not OMRDD. Thus, an interagency agreement was reached in which, on a prescribed date, OMRDD clinicians, DSS administrative staff and a CQC representative visited Woodcrest and the day programs attended by many of its residents for the purpose of conducting evaluations. The team found that 30 out of 104 residents attended no day program and remained idle at the home. The findings from this inspection also raised serious life safety issues. In particular, there was concern about the residents’ abilities to even exit the building during a fire owing to insufficient staff to assist residents in an emergency.

Charges and Counter-Charges

The information from these evaluations was incorporated by DSS into a statement of charges against the facility, on the basis of which DSS proposed a license revocation. The administrative proceedings on these charges, held before a State administrative law judge, spanned almost two years. During the course of the hearing, the operator brought a Federal court action against the Department of Social Services, alleging a State conspiracy to deprive him of his only source of income and to punish him for once speaking out against State policies. If the aim of the operator was to pressure the State into backing away from its charges in the revocation hearing, it didn’t work; the Federal complaint was found to have no merit and was dismissed.

Meanwhile, despite the administrative hearing to revoke the home’s license, there was no discernible improvement in the quality of care afforded to its residents who began approaching their Mid-Hudson Legal Services’ attorney and OMRDD seeking a transfer out of Woodcrest. Case managers began visiting on a daily basis and they began transferring residents to OMRDD family care homes, community residences, and, in special cases, to Wassaic Developmental Center as a point of transition to a more appropriate and happier community setting.

OMRDD Action

When the number of voluntary transfers began to reach close to forty, the operator openly defied State authority and denied OMRDD and DSS access to the facility. The Commission asked OMRDD Commissioner Elin Howe to intervene in the matter. Under Commissioner Howe’s directive, the OMRDD Counsel’s office and the Attorney General obtained an order to show cause in State Supreme Court and sought a temporary restraining order granting unobstructed access to Woodcrest. The OMRDD asserted its authority under Mental Hygiene Law Section 16.11 to .....

> conduct investigations into the operations relating to the provision of such services..[such as assistance in activities of daily living] to mentally retarded or developmentally disabled persons, by any entity which provides a residence for ... persons who are mentally retarded or developmentally disabled.

At the same time, DSS was granted a similar court order affirming its statutory right of access to the facility and, together with OMRDD, revisited Woodcrest. The agencies then set about transferring the remaining residents who were developmentally disabled. Even with the force of a Supreme Court order supporting the State agents, these visits were difficult; OMRDD/DSS staff were greeted with verbal abuse by the adult home staff and a cadre of non-disabled residents. More than anything, the experience of re-entering the home under these conditions served to confirm the Commission’s judgment that Woodcrest was no place for any of its residents to live.

Closure

In July 1992, the odyssey ended with the State’s hearing, victory and revocation of the Woodcrest license. Interagency cooperation among DSS, CQC, OMRDD and the Attorney General gelled around a common goal of “protection from harm.” It required that clinicians, managers, attorneys and support staff work together sometimes volunteering their time after normal working hours to assure a safe and productive environment for those cheated of their promise of a better life, and serves as a model for future replication.

But what about the individuals who left their home of many years? In July, this writer visited the Wassaic Develop-

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Letter

[*Ed. Note:* The following letter was sent to us from the sister of "Mildred," a case reported in our Jan-Feb 1992 Issue, p.6]

Dear Editor:

It is two years since my sister's death. She was in an Intermediate Care Facility at the time of her death. I am writing for many reasons. One reason is to make sure that others who have relatives in facilities are aware of their rights in regards to their relatives. Another reason is a selfish one on my part, but I'm hoping it will help to ease my guilt on the matter. A day does not go by when I don't think of sister and the tragic and inhuman way she was let to die.

In the two years prior to my sister's death, the facility where my sister lived steadily started going downhill from what I'd known it to be. Our mom visited weekly. I visited with her once a month or more. We visited on weekends. On weekends, I know there is usually less staff and not much activity, but it was different. It was beginning to seem that the residents were considered more of a bother or a nuisance and were being ignored quite often. My sister had always been such a delight, a happy smiling girl. She didn't smile anymore. I was worried she was being abused. Our mom was worried that if we said something, that the staff would take it out on her and things would get worse. We started proceedings to get her moved to a place closer to us but were informed it would be a long process. In the meantime we were told she had been given a cold shower by an aide and had numerous visits to the "time out" room. Her maladaptive behavior was increasing—she was not herself anymore—she'd had medication changes quite often. We thought all this time that she had been personally seen by a doctor. We were informed later that the doctor had never seen her but had prescribed psychotropic drugs at the advice of others. To be fair, I must say, we had to sign permission slips for these drugs but we did it thinking a doctor was seeing her and ruling out other possible medical problems before prescribing the medication. She was more or less being used like a "guinea pig." We were ignorant and trusted the system blindly. When a doctor was finally forced to watch a 10-minute video of my sister, he stated "she doesn't need any of these drugs. She is hyperactive and can be handled with a lot less potent drug."

It was too late at that point. The doctor (with disapproval from me, but what do I know) took her off cold turkey from medication she'd been on for years and from another she'd been on for a couple of months. I was glad she was not going to be so medicated but knew it shouldn't happen so fast. But, of course, he's the doctor and he knows what is best! We were told she would be monitored and were told on the phone and when I visited in person that she would be seeing the doctor. She died before that could happen. When we visited, 3 days before her death, she seemed to have a terrible cold—or so we were told. She couldn't talk, was very agitated and really wasn't aware we were there. I called back that evening and asked if her condition is common with the drug withdrawal. They told me yes—but she was going to see the doctor to be sure everything was okay.

I should have insisted she be taken to the hospital or should have taken her myself. What could I do—would the hospital have accepted her if I brought her in? I trusted they would take care of it. I must tell you that after her death, we learned that she didn't have a cold. She couldn't talk because she had spent the last two days in her room screaming and banging her head.

She was defenseless and at the mercy of others. I have to be honest, up to the last few months of my sister's life, I was not as involved as I should have been. I have my own family and life. I closed my eyes to what was going on and hoped she'd be okay. When I could see that the facility was going downhill and her condition was worsening, I became more involved. It was at that time we started proceeding to have her moved, but it was too late. This whole ordeal has really taken a toll on our mom. Even though she couldn't care for her at home anymore, she devoted her life to her. Since her death, mom has had numerous strokes which I believe were brought on by the stress.

This letter won't mean anything unless you remember it and use it as an example. Know your rights and even overstep them, if you have to. Don't trust that the proper medical attentions are being given. Don't trust that they are being properly cared for. Protect your loved one—don't take it for granted that everything will be okay.

Sincerely,
"Mildred's" Sister

> **Don't trust that the proper medical attentions are being given. Don't trust that they are being properly cared for. Protect your loved one—don't take it for granted that everything will be okay.**

Nominations Sought for Disability Advocate of the Year Awards

The Commission's Disability Advocate of the Year Awards are presented to New York State citizens for their outstanding contributions to improving the lives of persons with disabilities. Nominations are being sought for the 1993 awards.

Nominees should exemplify the spirit of advocacy. The theme for this year's Advocacy Awards is *Inclusion.* Consideration will be given to those who have included individuals with disabilities in community, family, school, or work settings. In so doing, they may have overcome significant barriers, identified and used new methods or resources, or persevered despite tremendous difficulties. The nominee may be a self-advocate, parent, employer, neighbor, public servant or any other individual who has made life in the community a positive experience for persons with disabilities.

Please submit a brief (250 words or less) description of your nominee's contributions, characteristics, and qualities. Include your own name and daytime telephone number so that we may reach you for additional information if necessary. Nominations must be sent by March 1, 1993 to:

Catharine McHugh
Commission on Quality of Care for the Mentally Disabled
99 Washington Avenue, Suite 1002
Albany, NY 12210-2895

A panel of judges, including self-advocates and representatives from the Disabilities Awareness Co-Sponsoring Organizations (The New York State Association for Retarded Children, the New York State Mental Health Association, the New York State Office of the Advocate, the New York State Association of Independent Living Centers, the New York State Developmental Disabilities Planning Council, the Alliance for the Mentally Ill, and Catholic Charities) will review all nominations and make final decisions. The awards will be announced in April 1993.

Woodcrest

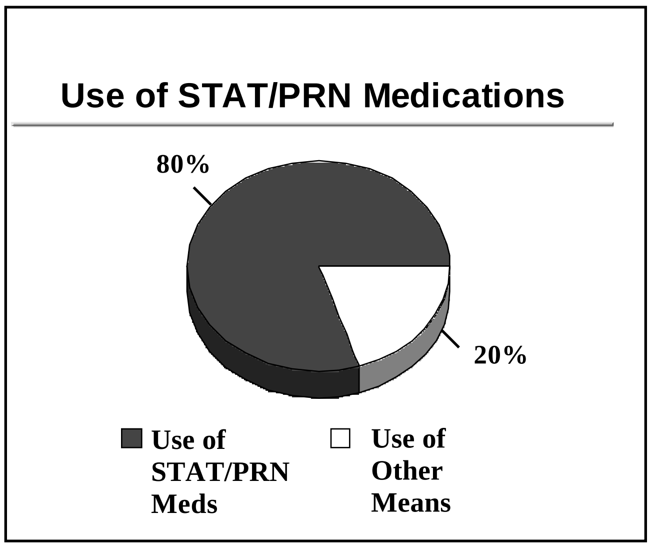
Continued from Page 8

mental Services area; I interviewed and observed many of the former Woodcrest residents. They were, on the whole, happier, more well-nourished, and engaged in a more nurturing social climate than before their transfer. The transformation benefits were reaffirmed in day program participation, where there was consistent attendance. In the instance of one resident who had suffered the indignities of both Willowbrook and Woodcrest, the change brought about by her new family care provider was almost miraculous. While at Woodcrest, this young woman with a right hemiplegia (paralysis of one half of the body) was made to remain in a wheelchair as a form of restraint. In her new family care home, she is fully ambulatory and her self-abusive behaviors have been almost entirely extinguished. Her family care "mother" is a trained nurse and family friend who uses common sense and sensitivity in helping her to assume and display socially acceptable behavior. This placement has won the approval of both the Willowbrook Consent Decree Special Master and the Consumer Advisory Board. In a real sense, a life was rescued, against heavy odds.

And finally, what about the family who first brought the issue to the Protection and Advocacy Program? The move has benefited the young man in question and he may quite possibly experience a re-unification with his family, thanks to those who earnestly believed that the system could work—even if it had to be pushed.

Medication of Children

Continued from Page 1



dren's continued need for medication; and there is a heavy reliance on medications to control the children's behavior with few effective individualized plans for behavior management and apparently little assistance from clinicians in dealing with crisis behaviors."

The Commission studied a sample of 94 children from 8 State- operated children's psychiatric centers and children and youth units at adult psychiatric centers. Nearly two-thirds had been victims of sexual or physical abuse or neglect prior to hospitalization, and many had histories of multiple abuse/neglect. Nearly 80 percent of the children studied were adolescents, and most had experienced previous out-of-home placements, which is common for abused children with dysfunctional family backgrounds.

Specific Findings

Among the Commission's findings:

❑ In only 8 of the 94 cases reviewed (9%), appropriate written informed consent to give medication to minor children was obtained from parents or guardians. Many cases lacked adequate or accurate information, or omitted details on how consent was obtained and what information was provided. In almost half the cases sampled, there was no evidence in the case record that parents/guardians had been given such information;

❑ aided by Pharmakon, a computerized drug monitoring system, most facility physicians were complying with accepted medical practice, as well as OMH's drug prescribing and administration guidelines. Dosage limits were respected, the consequences of combining drugs were considered, drug benefits and side effects were monitored, medication decisions were documented, and senior psychiatrists were consulted when appropriate;

❑ contrary to the advice in OMH's *Psychotherapeutic Drug Manual,* facilities in the study failed to use drug-free periods to determine whether medication was still necessary, and over half the children studied lacked individualized behavior management plans. The use of "stat" (immediate) or "PRN" (as needed) medication orders to deal with agitated and assaultive behavior occurred in 80 percent of the cases studied, and direct care staff bore the brunt of dealing with agitated children, without the guidance of behavior plans developed with clinical staff; and

❑ systems to reward positive behavior and punish negative behavior were primarily used in facilities as "ward management tools" and did not address children's treatment goals or specify appropriate staff responses to children's problem behaviors.

Psychoactive medication, although often a stabilizing and positive factor in treatment, can have uncomfortable or debilitating side effects. Adult patients and the parents/ guardians of minor patients cannot make decisions about whether to accept proposed treatment without information about its risks and benefits, including possible side effects. OMH regulations presently do not require informed consent for administration of psychotropic medications, but require that any proposed treatment such as medication be explained to patients, including information on foreseeable risks, expected benefits and alternative treatments, and permit patients to refuse treatment, except in an emergency.

The study and subsequent conversations with the Office of Mental Health have identified OMH's substantive disagreement with the Commission on important issues the Commission considers essential safeguards for patients who are prescribed psychotropic medications. These disagreements center upon an effective and accountable process for ensuring that parents or guardians of minor children are given sufficient accurate information about the risks and benefits of the medications being prescribed for their children to enable them to provide informed consent for the administration of these medications. There are similar disagreements about an accountable and effective process to ensure that the patients themselves are adequately informed about the intended effects of such medications and their risks and benefits.

The Commission report recommends OMH require its facilities obtain informed consent for administration of psychotropic medication from parents/guardians of minor children, and consider methods to secure informed consent for administration of psychoactive drugs from ALL patients, including alternative methods for mentally incompetent patients. The Commission report also urges enforcement by OMH of its own regulations by requiring facility physicians to document in patients' records the medication information shared with patients, and their responses, as well as with parents and guardians of minor children.

OMH has agreed to require written informed consent from parents/guardians for minors in its facilities, but not from facilities it licenses. It also declined to require documentation of physician discussions on the use of medication, which it asserts occur routinely, although such an obligation is articulated in OMH policy. The Commission believes that there needs to be accountability to assure that these discussions do in fact take place. The absence of any reliable means of assuring that clinicians are complying with the policy is deeply troubling.

Recommendations

The Commission report also recommends OMH study its facilities' reliance on PRN and STAT medication and explore use of alternative means to control problem behavior, including use of behavior plans and other methods to encourage positive behaviors, and urges OMH continue efforts to increase clinical staff presence on units during evenings and weekends, when problem behaviors are most common. OMH agreed to study use of PRN/STAT medication as part of its review of behavior management procedures.

Additionally, the Commission report urges OMH to remind facility directors of the OMH *Psychotherapeutic Drug Manual's* endorsement of medication-free periods and require facilities to ensure drug-free periods for long-term patients. OMH agreed to revise the *Manual* to stress the need for monitoring of each child's medication, but would not recommend drug-free periods for all patients.

The Commission conducted the study in conjunction with its legal responsibility under the Child Abuse Prevention Act of 1985 (CAPA), to investigate all allegations of child abuse and neglect in state mental hygiene facilities. CAPA investigations frequently involved allegations of abuse stemming from facility staff attempts to control children's difficult behavior and often included use of STAT and PRN medication.

Copies of the report may be obtained from the Commission for $10.

Counsel's Corner

Continued fom Page 3

Endnotes

[1] J. Kelner & R.S. Kelner, Tort Liability for Sexually Transmitted Diseases, N.Y.L.J., Nov. 12, 1987, p. 1; see also, Comment, AIDS in the Workplace: A Legal Guide, 22 Conn.L.Rev. 943 (1990); Note, Tort Liability for the Transmission of the AIDS Virus: Damages for Fear of AIDS and Prospective AIDS, 45 Wash. & Lee L. Rev. 185 (1988); Baruch, AIDS in the Courts: Tort Liability for the Sexual Transmission of Acquired Immune Deficiency Syndrome, 22 Tort & Ind. L. J. 165 (1987); Note, Viability of Negligence Actions for Sexual Transmission of Acquired Immune Deficiency Syndrome, 17 Cap. U. L. Rev. 101 (1987); Note, You Never Told Me. . . You Never Asked: Tort Liability for the Sexual Transmission of AIDS, 91 Dick. L. Rev. 529 (1986); Note, Negligence as a Cause of Action for Sexual Transmission of AIDS, 19 Tol. L. Rev. 887 (1988-89); Annotation, Tort Liability for Infliction of Venereal Disease, 40 A.L.R. 4th 1089 (1985).

[2] See, *Youngberg v. Romeo,* 457 U.S. 307 (1982).

[3] Emotional injury is not normally recognized without a corresponding physical injury, although this might be changing with the advent of AIDS which causes significant emotional injury usually well in advance of physical symptoms. See, H.H. Lipsig, AIDS Phobia and Negligent Infliction of Emotional Distress, N.Y.L.J. March 26, 1992 at p. 3; See also, *Carroll v. Sisters of St. Francis Health Services, Inc.*, 61 U.S.L.W. 2291 (Tenn. Ct. App. No. 02A01-9110-CV-00232, Oct. 12, 1992).

[4] Negligence is gauged by an ability to anticipate and the risk must lie within the range of apprehension. Foreseeability is the quintessential and indispensable requisite of negligence, the "conditio sine qua non." See *Ward v. State,* 81 Misc. 2d 583, 366 N.Y.S.2d 800 (1975).

[5] *Billo v. Allegheny Co.,* 328 Pa. 97, 105, 195 A. 110, 114 (1937)(dicta), as cited in 70 Cornell L. Rev., *infra* note 8, at p. 119-120.

[6] *Blanco v. Sullivan,* N.Y.L.J., Nov. 16, 1992 at p. 34.

[7] See *Maharam v. Maharam,* 123 A.D. 2d 165, 510 N.Y.S. 2d 104 (1st Dept. 1986), mod. & aff'd. 177 A.D.2d 262, 575 N.Y.S. 2d 847 (1st Dept. 1991); see also, *supra* note 3.

[8] See e.g., N.Y. Public Health Law, Section 2307; see generally, Note, Liability in Tort for the Sexual Transmission of Disease: Genital Herpes and the Law, 70 Cornell L. Rev. 101, 116 (1984).

[9] *Petri v. Bank of New York Co., Inc.,* 582 N.Y.S. 2d 608 (Sup. Ct., N.Y.Co., 1992).

[10] Cf., *Livingston v. Gribetz,* 549 F. Supp. 238, 244 (1984).

[11] See N.Y. Public Health Law, Sections 2504 and 2805.

[12] See e.g., 14 N.Y.C.R.R. Sec. 624.4 (b)(2).

[13] Traditionally the courts have been the final arbiters of a person's competency, whether the legal issue is the validity of a will or medical consent. Indeed, the highest court in New York has said that the determination of competency is "uniquely judicial" in some instances. See, *Matters of Eichner and Storar,* 52 N.Y. 2d 363 420 N.E. 2d (64, 438 N.Y.S. 2d 266, cert. denied, 454 U.S. 858 (1981)).

[14] Quoted in Note, Standards of Conduct, Multiple Defendants and Full Recovery of Damages in Tort Liability for the Transmission of Human Immunodeficiency Virus, 18 Hofstra L. Rev. 37, 47 n.48 (1989).

[15] See *supra* note2.

[16] Supra note 8, 70 Cornell L. Rev. at p. 127-28.

[17] See e.g., *Barbara A. v. John G.,* 145 Ca.App.3rd 369, 193 Cal.Rptr. 422 (Ct.App. 1st Dist., 1983).

[18] *Cowe v. Forum Group Inc.,* 60 U.S.L.W. 2114, 2115 (Ind. Sup. Ct. No. 41SO4-9107-CV-569, July 25, 1991).

[19] See *Laurie Marie M. (Anonymous) v. Jeffrey T.M.(Anonymous),* N.Y.L.J.

Protection and Advocacy for Individual Rights Program: First Year Case Examples

The Protection and Advocacy for Individual Rights (PAIR) program extends the advocacy services provided by the Client Assistance Program (CAP) and Protection and Advocacy for Persons with Developmental Disabilities Program (PADD), so that a person receiving assistance from Independent Living Centers or otherwise not qualified for PADD services will be able to obtain representation in any matter affecting their legal rights, such as employment and housing discrimination, with which CAP or PADD presently is not permitted to deal under the federal law. These legal and other advocacy services to protect the rights of disabled individuals also will assist in implementation of the Americans with Disabilities Act (ADA).

Less than a year ago, the Commission received a PAIR grant from the Rehabilitation Services Administration of the U.S. Department of Education. The award to the Commission provided additional funding to New York Lawyers for the Public Interest (NYLPI) in New York City and Neighborhood Legal Services (NLS) in Buffalo to provide assistance in the New York City and Western New York regions. Based on less than six months of PAIR activity, the two New York State PAIR project sites have already opened over one hundred individual advocacy cases for persons with disabilities. Some of the typical activities under PAIR have been the following:

❑ ADA Compliance Project

This initiative is designed to increase public awareness of the responsibilities of owners of buildings under the ADA provisions on public accommodations and to monitor the Department of Justice enforcement of those provisions of the ADA. Complaints were filed with the Department of Justice against four buildings, accompanied by a demonstration at the Empire State Building by Disabled in Action, and extensive media coverage. A follow-up meeting was held with a Department of Justice official to review the Department's procedures for processing ADA complaints. A settlement was reached with one building, a hotel, which constructed ramps outside the building to provide entry and on the lobby floor for access to the restaurant, provided accessible telephones, public bathrooms, seven ADA compliant guest rooms and special arrangements for the hearing impaired. The settlement benefits hundreds of mobility impaired persons annually who use facilities at the hotel. The Department of Justice has not yet ruled on the remaining three buildings.

❑ Working at Home

The Multiple Sclerosis Society contacted NYLPI for assistance in a case involving a man with MS. He had worked at home for several months when his unit was being transferred upstate. He wanted to continue working at home, but his employer allegedly tried to coerce him into taking disability retirement. The MS Society sought advice from NYLPI on whether the employer's actions constituted employment discrimination. NYLPI's advice subsequently led to the employer deciding to continue allowing the client to work at home.

❑ Survey on Compliance with ADA

NYLPI undertook a survey of employment applications of twenty major employers in New York City to determine compliance with the Americans with Disabilities Act. The survey indicated that at least 45 percent of employers surveyed had at least one question on their entry-level job application in violation of the ADA. NYLPI wrote to noncompliant employers, and all but one have made changes to remove offending questions.

❑ Learning Disability and Curriculum Modification

A Committee on Special Education (CSE) in western New York refused to classify a very bright seventh grade student with severe learning disabilities under the Individuals with Disabilities Education Act (IDEA). The severe learning disabilities significantly limited her in reading, written expression, and spelling. However, because she is so bright, she has been able to obtain passing grades in school and the CSE refused the classification. Also, because of her ability to function quite well in the regular class environment, she was not considered "developmentally disabled" and thus ineligible for services under the Protection and Advocacy for Persons with Developmental Disabilities program. With PAIR representation, NLS was able to get the district to identify her as a disabled student under §504 and provide modification to her regular class curriculum. In the process the district created a district-wide §504 review procedure.

❑ Sport Participation

A 16-year-old student underwent a kidney transplant several years ago. Prior to his kidney replacement surgery he was in quite poor health but was nevertheless required to participate in gym activities. Following surgery his health was much improved. Although he participated in most gym activities, the school district would not let him play interscholastic baseball or basketball, even though his treating physicians indicated it was safe for him to do so. Further, his counselor stated that it was important for his self-esteem to participate in as many normalized activities as possible.

The NLS PAIR attorney initiated a successful action in New York State Supreme Court under §3208-a of the Education Law. Section 3208 of the Education Law provides for the participation of a student with disabilities in sports if the student releases the school district from liability. The court ruled that the student qualified for this waiver provision. As a result the student is now able to participate in these sports.

❑ Home Aide Service Continued

A 37-year-old man with quadriplegia acquired his disability after the age of 22, so he was not "developmentally" disabled or eligible for services under the PADD program. Because he is under the age of 60, he was not eligible for services by the Legal Services for the Elderly program in Buffalo. He had 24-hour aide services because of the severe nature of his disability after he was discharged from a county home and infirmary to live in the community. The county agency which coordinates the provision of aide services was threatening to reduce his aide services by requiring him to participate in a shared aide program, even though his treating physicians stated that this was medically inappropriate. With the NLS PAIR attorney's involvement, the county finally agreed to continue his 24-hour aide service.

❑ Need for Special Education Services Satisfied

A six-year-old student with learning disabilities has a seizure disorder and attention deficit disorder. He is also very bright and functions above grade level. Nevertheless, he was recommended to repeat first grade because of his learning difficulties. However, the school district refused to identify him as a disabled student or provide special education services to him.

Because the student is so high functioning, he was not eligible for services under the PADD program. With the NLS PAIR attorney's involvement, the district finally agreed to provide special education services. As a result, the student was provided with resource room placement, and test modification provisions, including extended time on tests.

PAIMI Annual Public Hearings

by Sylvia Wheeless

During September, the Commission provided three opportunities for public comment on the activities and priorities of the federally funded Protection and Advocacy for Individuals with Mental Illness program (PAIMI), which is administered by the Commission. For the first time, these hearings were held on the grounds of three State psychiatric centers to make them more readily accessible to individuals who are currently inpatients in the psychiatric system.

Commission Chairman Clarence Sundram, Commissioner William Benjamin, staff from the Commission and from regional offices which provide services under the PAIMI Act all heard testimony from patients in the mental health system, their family members, mental health services providers and representatives of other advocacy organizations during the three days of hearings, which were held at Pilgrim PC, Capital District PC, and Buffalo PC. Written and telephone comments were also received from individuals who were unable to attend the hearings. More than fifty individuals participated in the hearings and comment process this year.

Topics addressed during the hearings were diverse and ranged from requests for assistance with individual problems currently being experienced by individuals to questions about decisions made by specific facilities which affect patient care. The past work of the PAIMI program received both praise and criticism. Many participants focused comments on the need for expanded services, both in advocacy and in mental health care as well as in family supports. Relatedly, many participants expressed concern over decreases in funding levels for mental health services and described the impact of such decreases on specific groups of individuals.

Some specific areas of focus during the three days included:

- ❑ residents' rights in adult homes—some individuals spoke about rights violations and residents in adult homes often do not feel safe in making a complaint to an outside source of advocacy;
- ❑ cultural sensitivity of mental health programs—the needs of mentally ill individuals who do not share English as a usable language, and the needs of individuals who are from diverse cultural backgrounds for culturally sensitive and language-appropriate services;
- ❑ the need for more family involvement in the PAIMI program—a suggestion of increased communication between local and statewide Alliance for Mentally Ill groups and regional PAIMI staff has already been acted upon;
- ❑ employment of mentally ill individuals—problems encountered in trying to enter the job market; and
- ❑ complaints about conditions in multiply-disabled units operated by the Office of Mental Health—follow-up by Commission investigation.

PAMII or PAIMI?

The "PAMII" program has become the "PAIMI" program. When the Act was reauthorized last fall, Congress changed the name from Protection and Advocacy for Mentally Ill Individuals to Protection and Advocacy for Individuals with Mental Illness. People first!

**NYS Commission on
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for the Mentally Disabled**
99 Washington Avenue
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ADDRESS CORRECTION REQUESTED

SDMC Program Seeks More Volunteer Panelists

The Surrogate Decision Making Committee Program (SDMC), in view of recent legislation promoting its expansion [see *Quality of Care*, Issue 53, Aug-Sep 1992, p. 9] is seeking more volunteers to serve as committee panelists. The SDMC program is an innovative and award-winning program administered by the Commission, which provides an alternative to the courts for providing consent or refusal for medical treatment for mental hygiene facility residents who are unable to provide their own informed consent and have no family or guardian to provide surrogate consent on their behalf. The program has been very effective in providing timely consents to major medical treatment.

Composition of the Panels

The Committees are comprised of four-member panels who serve as the surrogate decision-making body. The panels must include a health care professional (medical doctor, nurse, clinical social worker), an attorney, a former patient or relative (persons who have been consumers of mental health services or who have family members who have been consumers), and an advocate (person with expertise or interest in the care of persons with mental disabilities). The panelists review documents, called declaration forms, regarding an individual resident's capacity and need for treatment. The decisions are made by the panels after a hearing to review each declaration. Expenses are reimbursed.

Training Provided

Panel members assist people with mental disabilities by protecting the person's autonomy and best interests in decision-making. Training is provided by the Commission and indemnification from liability is provided by the State. Furthermore, the work load is manageable and foreseeable because cases are reviewed by the panelists prior to the hearing; the hearing is held pursuant to the Mental Hygiene Law Article 80; and, finally, panel determinations are, in most cases, made immediately after the hearing. The nature of these procedures allows the panel members to select the amount of participation which is conducive to his or her other obligations during a specific period of time.

Immediate Needs

Panel members, especially attorneys, are immediately needed for the Rockland, Dutchess, and New York City areas. As the program expands, members will be needed throughout the state.

If you are a health care professional, attorney, consumer or relative, or advocate with expertise or interest in the care of persons with mental disabilities and are interested in participating as a volunteer in this noble service, please contact:

Anne Reed, Director
SDMC Program
NYS Commission on Quality of Care
for the Mentally Disabled
99 Washington Avenue, Suite 1002
Albany, NY 12210
Tel. (518) 473-8683

Another PAIMI Clozapine Victory

Neighborhood Legal Services, Inc., the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program in the western region of New York, has scored a substantial victory for the rights of outpatients for whom Clozapine has been prescribed. Building on last year's PAIMI success at New York Lawyers for the Public Interest, Inc. [see *Quality of Care*, Issues 47 and 48, Jan-Feb and April-May, 1991] which saw Clozapine included in the Medicaid formulary—meaning that Medicaid would pay for this drug for outpatients—NLS represented an individual for whom Clozapine had been prescribed for a diagnosis other than schizophrenia.

The client in western New York carried a diagnosis of manic depressive illness, and hence was denied Medicaid payment for a prescription for Clozapine, as Medicaid had previously only approved payment for the drug for persons labeled with a diagnosis of schizophrenia.

During a fair hearing, PAIMI advocates presented expert testimony that Clozapine was necessary and would be effective in treating this individual, who wanted this form of treatment. A favorable decision was received after the hearing.

This decision is extremely important because it opens the door for other individuals to receive Medicaid funding for Clozapine on the basis of recommended treatment *rather than* diagnosis. If other advocates would like information about the decision, please contact Ellen Lawson at Neighborhood Legal Services, Inc. Telephone: (716) 847-0650.

Quality of Care

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for The Mentally Disabled

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