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Sexual Knowledge and the Capability of Persons with Dual Diagnoses to Consent to Sexual Contact

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Capability to consent to sexual contact was determined by an interdisciplinary team for thirty-one individuals residing on a unit serving dually diagnosed individuals (mental retardation and a psychiatric disorder). Capability status was strongly related to sexual knowledge, level of mental retardation, social adaptive age, participation in a sex education course, psychiatric diagnosis and other capabilities to consent. The sexual knowledge demonstrated by capable individuals is described. The multi-stage evaluation procedure and problematic issues are discussed in terms of legal implications, the situational nature of capability status, and the need for a data base to facilitate capability determinations.

KEY WORDS: Capability; sexuality; informed consent; dual diagnosis.

Historically, persons with mental retardation were often considered to be asexual or to have aberrant sexual interests in need of social controls. Lately, however, educators, treatment providers, and society at large have become increasingly aware of the legitimate sexual needs and interests of all handicapped persons, including those with mental retardation. This has resulted in an increased emphasis on sexuality training programs and on developing agency policies regarding sexual activity. Regulations in New York (1) affirm the right of all individuals served in agency facilities to express sexuality within the limitations of their consensual ability to do so. (Throughout this paper, we will use the expression "consensual ability" interchangeably with the expression "capability to give informed consent to sexual contact.") The regulations do not

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provide much guidance on what consensual ability is, however, or on how it is to be assessed. New York's draft guidelines on sexuality (2), drawing in part on a New York court case (3), supply some direction. These guidelines indicate that those evaluating an individual's consensual ability should address the person's ability to make a decision based on knowledge of the nature of sexual contact, its possible consequences, and the social and moral context in which it occurs. New York State's Penal Law (4) defines sexual contact as touching the intimate parts of a person not married to the actor to gratify the sexual desire of either party. According to the law, contact where one or both parties lack consensual ability may be a crime. Because of this, staff are required to report all sexual contact between non-consenting individuals to the appropriate authorities. The guidelines do not indicate to what extent a capable person needs to understand the relevant issues; neither do they discuss the complex, situational nature of consensual ability. They do state, however, that evaluations of capability to consent to sexual contact should be conducted for all individuals served. In view of the current emphasis on the rights of all people to self expression, including those with developmental disabilities, it is likely that practitioners in other states will also need to determine consensual ability for many of the individuals that they serve.

A review of the literature revealed studies of the relationship of the sexual knowledge of persons with mental retardation to variables such as parental attitudes (5); IQ and adaptive behavior (6); IQ, adaptive behavior, sex, and place of residence (7); institutionalized v noninstitutionalized residence (8); participation in a sex education program (9); and attitudes about sexuality, marriage, and parenting (10). No studies were found relating consensual ability to sexual knowledge or to any other variables. This kind of information would provide guidance regarding what standards to apply when evaluating the ability of people to give informed consent to sexual contact; it would also give evaluators the confidence of knowing they were following practices recognized as valid in the field.

Absent this information, our plan was to use a formal tool to assess each individual's sexual knowledge and then to evaluate other relevant issues by involving a broad cross section of the interdisciplinary team in the capability determination process. The team would need to apply standards which allowed a reasonable level of self-determination but which satisfied the treatment provider's duty to protect individuals from harm. When the evaluations were completed, capability determinations could be correlated with variables of interest available in the historical records. It was anticipated that the findings, though preliminary, would contribute towards working guidelines for future evaluations and towards a data base from which professional standards for judgements of consensual ability could evolve.

Previous research on capability issues (11) led to the hypothesis that indi-

viduals with moderate and severe mental retardation were not likely to be found capable of giving informed consent to sexual contact while some, though not all, individuals with mild mental retardation would be found capable. We also hypothesized that capable individuals, relative to individuals determined to be incapable of giving informed consent, would have higher scores on a test of sexual knowledge, higher social adaptive ages, more exposure to sex education courses, and a greater likelihood of having previously been found capable of giving informed consent to at least one other issue involving care and/or treatment. Though we had no specific hypotheses on the issue, we intended to examine the relationship between psychiatric diagnosis and consent status in our sample. We also expected that some issues, particularly those related to the situational nature of consensual ability, would pose more difficulty than others for the team to resolve and we planned to describe and comment on them.

METHOD

Subjects

The subjects were 16 males and 16 females, residing on a Multiply Diagnosed Unit (MDU) at a state operated facility. Most carried a diagnosis of Mental Retardation and a diagnosis denoting a psychiatric condition. The median age was 38 years, with a range of 21 to 65. Twenty met DSM-III-R (12) criteria for Mild Mental Retardation; six met the criteria for Moderate Mental Retardation; five met the criteria for Severe Mental Retardation. One individual, whose IQ tested in the low 80's, was not diagnosed as manifesting Mental Retardation. Ten individuals were diagnosed as manifesting some form of Schizophrenia; 11 were diagnosed as presenting a Personality Disorder; five were diagnosed with various other psychiatric conditions. Six had no psychiatric diagnosis. Twelve had completed the 40-hour sex education course offered on the MDU (13,14).

Procedure

A multistage evaluation procedure was used, consisting of the following steps:

Formal Testing

Each individual was tested with the Socio-Sexual Knowledge and Attitudes Test (SSKAT) developed by Wish, McCombs, and Edmonson (15). The

SSKAT includes questions designed to assess both knowledge and attitudes about sexuality; these are scored separately. Many of the questions on this test are presented with pictorial aids. Often, the examinee can respond by pointing to the correct alternative or by indicating "Yes" or "No." This format allows one to express knowledge and attitudes in ways which do not rely heavily on verbal skills.

Each author tested eight of the males. The unit social worker (a woman) tested all of the females except two, who were tested by the first author in the presence of a female staff member. Prior to the testing, the examiner presented a general explanation of the purpose of the test, sought the examinee's permission to begin, and stressed that testing could be discontinued at any time if the examinee asked to stop. One person declined to begin the test and as a result was not included in the remainder of the study. The other 31 individuals completed the entire SSKAT. After the test was completed, the examiner thanked the examinee for his/her cooperation and answered any questions the examinee had related to the evaluation. Protocols were scored according to the procedures described in the SSKAT manual (15). SSKAT knowledge scores (not attitude scores) are used in subsequent data analyses.

Written Announcement of Formal Team Meeting

Several days prior to a special meeting, the first author sent a memorandum to all staff on the MDU, listing the individuals whose capability would be determined at that meeting. The memorandum asked staff to think about the ability of those named to consent to sexual contact. It also asked those who could not attend the meeting to share their opinions and relevant information with those who would be attending. In many cases, this memorandum stimulated considerable discussion, the results of which were shared at the formal team meeting.

Formal Team Meeting

The team met seven times in a two month period to complete its review of all 31 individuals. Five to 10 staff members were present at these meetings. The first author (the unit psychologist) was always present and the unit social worker was present at all meetings except one. Usually, the person primarily responsible for implementing the individual's plan of care was present, along with direct care, administrative, and nursing staff. In all, 22 different MDU staff participated in at least one meeting. All staff had worked on the MDU for over a year, knew the individuals' histories, and had had extensive interactions with them. The median number of years of experience in the health, mental

health and/or mental retardation fields of employees who participated in at least one meeting was eight; the range was three to 24.

Each meeting began with the first author noting that to be capable of giving informed consent to sexual contact in New York State one needed to know what sexual acts were, to know their possible consequences, and to understand how sexual acts would be viewed by others (i.e., their social and moral context). He also noted that the law provided no absolute standard for how much one needed to know or how well one had to understand and that the team needed to apply standards which made sense. Following this, the first author briefly summarized the knowledge demonstrated on the SSKAT by the individual being evaluated. (This summary never included information regarding test *scores* because it was thought that the team might be influenced more by the score itself than by the knowledge it reflected.) A general discussion of the individual's interpersonal/sexual functioning followed. Always included in this discussion were considerations of the person's ability to avoid victimization, of his or her observing privacy in sexual matters, and of any sexual behaviors the individual presented which might cause harm to him/herself or others. Where indicated, we also discussed the person's attitudes about key sexual issues and planned interventions to address identified needs. The discussion on each person lasted five to 20 minutes, depending upon the number and complexity of the issues presented. The team then reached a consensus on the capability of each person evaluated to give informed consent to sexual contact.

There were four possible determination categories: (1) Capable of giving informed consent. (2) Capable of giving informed consent with qualifications. Qualifications could be based on various issues (e.g., sexual dysfunction, probable adverse reaction to sexual contact, poor impulse control, etc.). (3) Not currently capable of giving informed consent but possibly capable with further training. These persons were recommended for the sex education course offered on the MDU. (4) Not currently capable of giving informed consent and not likely to become capable, even with further training. Some of these persons may have been recommended for specific kinds of training, such as how to avoid victimization.

Documentation of the Team's Decision

Written minutes describing the team's discussion and decision were prepared and filed in each individual's chart.

Counseling for Those Judged Capable

The first author, as unit psychologist, had a private counseling session with each capable individual, including those with qualified capability, where

the social and legal implications of the client's capability status were presented and discussed. This discussion included the information that sex between unmarried persons on the facility grounds was against agency policy. The session was documented in the person's chart. Those found not capable were not specifically counseled regarding their capability status but were counseled on issues such as privacy and avoiding victimization, according to treatment team recommendations.

Subsequent to the above multi-stage evaluation procedure, the authors reviewed the individual's records to determine for each the diagnosed level of mental retardation, psychiatric diagnosis, consent status for psychotropic medication and/or restrictive behavioral interventions, and whether or not the person had completed the sex education course offered on the MDU (13,14). This information was available to all staff. Nevertheless, the individual's performance in the sex education course was the only aspect discussed at the team meetings. Subsequent to this record review each person was further evaluated for social-adaptive functioning with the Scales of Independent Behavior, Short Form (16).

RESULTS

The relationships between individuals' capability to give informed consent to sexual contact, as determined by the treatment team, and each of the other variables included in this study are summarized in Table 1. For purposes of analysis, we designated two determination categories: capable and incapable. The capable category included those the team found fully capable and those found capable with qualifications. The incapable category included those not currently capable, whether or not there was a possibility they could become capable with further training. In addition, the one person whose IQ tested in the low 80's and who was not diagnosed as mentally retarded was included in the Mild Mental Retardation group.

The variable of capability status correlated significantly with all other variables of interest. It correlated strongly with SSKAT knowledge scores (r point biserial = .73, $p < .01$); with level of mental retardation ($z = 3.08$, $p < .01$) by a Jonckheere Test (17); with adaptive behavior age (r point biserial = .70, $p < .01$); with completion of the sex education course ($X^2 = 5.33$, $p < .05$); with capability to give informed consent in other areas (Jonckheere Test, $z = 3.82$, $p < .01$); and with psychiatric diagnosis (Phi Coefficient = .75, $p < .01$).

In addition to these relationships, we were interested in the types of knowledge demonstrated by persons in our sample. Capable individuals as a group tended to have higher SSKAT knowledge scores, with raw scores

Table 1. Relationship of Capability Status to Variables Studied

	Capable	Incapable
Number of Persons	13	18
SSKAT Knowledge Scores		
Above 90%	9	1
80%-89%	4	2
Below 79%	0	15
Level of MR		
Mild	13	7
Moderate/Severe	0	11
Adaptive Behavior Level		
ave. (years)	10.8	6.2
s.d. (years)	2.3	2.1
Completion of Sex Educ. course	10	2
Capability to consent to other issues[a]	9 of 12	0 of 17
Psychiatric Diagnosis[b]		
Schizophrenia	0	10
Personality Disorder	8	3

[a]Refers to team's independent judgment of capability to consent to psychotropic medications or to restrictive behavioral interventions. Not all subjects received one or both of these treatments.
[b]Other diagnostic categories had too few people to discuss for comparisons.

ranging from 319 (82%) to 381 (98%). This compared with raw scores for incapable individuals ranging from 79 (20%) to 365 (94%). Those scoring between 82% and 94% and found incapable were judged as such because they lacked what the team considered to be critical knowledge about conception, birth control, and/or venereal disease. In each case, the team recommended further training, with the expectation that the person would become capable.

While helpful as a general guide, SSKAT scores do not provide information about the specific strengths and deficits in sexual knowledge possessed by the capable person. To determine this we examined each individual SSKAT protocol. A summary of the knowledge demonstrated by capable persons appears in Table 2. In almost every case, at least 11 of the 13 individuals judged capable answered the SSKAT questions referred to correctly. Brief instruction was all that was required to correct lack of information (or misinformation) in those judged capable of giving informed consent.

DISCUSSION

All of our hypotheses were supported, as the team's judgements of capability to consent to sexual contact were strongly associated with sexual knowledge (SSKAT scores), diagnosed level of mental retardation, adaptive behavior

Table 2. Sexual Knowledge Possessed by Capable Clients

Knows names (maybe slang terms) for sexual organs and their sexual function(s): 5, 6, 10, 11, 12, 13[a]
Correctly identifies various sex acts (heterosexual intercourse, masturbation, male and female homosexual activity) when shown pictures of them: 145, 151, 160, 167
Knows where a man must put his penis to make a baby get inside a woman and where a baby comes out when it is born. Also knows that other activities, such as going swimming, sitting on the toilet and getting married cannot make a woman get pregnant: 93, 94, 95, 96, 97, 98, 99, 119, 120, 121
Says that it is wrong to have sex with family members (other than spouses) and with children: 55, 56, 57, 58, 59, 77, 78, 80, 81
Says that it is not easy to raise a baby; that it costs money; that a baby sometimes needs to see the doctor; and needs food, clothes and toys: 104, 105, 107, 108, 109, 110
Identifies pictures of birth control pills and condoms and says what a woman can do to keep a baby from getting inside of her: 121, 122, 123
Six of the 13 capable said that if a woman is on the pill there is no way she could get pregnant: 138
None could identify pictures of an IUD or diaphragm: 132, 135[b].
Says that sexual acts should be done in private, but may have a different definition of "private" than most people, perhaps because of years of institutional living. May say, for example, that it is okay to have sex in a park if no one else can see or in a deserted classroom: 83, 148, 149, 154, 155, 165, 166
Says that most people do not think that it is okay to perform homosexual acts: 163, 170
Says that sexual acts make one feel good, but may also indicate that they sometimes make one feel bad. When asked further, indicates people feel bad because they might get caught and/or that it is "wrong" (either according to residence rules, the law, or religious teachings): 88, 159, 174
Knows that one can catch diseases from sexual intercourse, but may not know that these are called "Venereal Diseases": 176, 178
Ten of the 13 capable said that one could catch sexually transmitted diseases from a toilet seat (177) but all said one could not get them from other sources, such as shaking hands or being in a social group: 182, 183, 185, 186. The misinformation about toilet seats was easily corrected.
Says that it is not okay for people with venereal diseases to have sexual intercourse: 181, 184. Says that other interpersonal activities are okay to do: 182, 183, 185
Says it is wrong to force sex on someone who does not want it: 216, 219, 220, 223, 224, 225
Says it is wrong to peek into someone's window: 217
Says it is wrong to pay or to be paid to have sex: 86, 87
Says it is not okay to have sex with a stranger: 85

[a]These numbers denote questions on the SSKAT which assess this knowledge.
[b]These devices were discussed in the sex education course, but they were never actually presented to the participants to see and handle, as were condoms and birth control pills.

age, participation in sex education, and consensual ability in other areas. Though the small sample size precludes extensive multivariate analysis, many of the variables evaluated in this study are likely to be interrelated. Diagnosed levels of mental retardation, for example, are based partly on social adaptive functioning. Further, selection of individuals for the full sex education course (made well before our study began) was based on the treatment team's decision that they possessed the learning and reasoning ability to profit from it. All 10 of the persons who took the sex education course and who were found capable were diagnosed with Mild Mental Retardation; the two who took the course and

were not found capable were diagnosed with Moderate Mental Retardation and had been assigned to the course mainly so they could learn how to avoid victimization. Because persons were not randomly assigned to the sex education course, no conclusions regarding a causal relationship between participation and the team's judgements of capability to consent to sexual contact are possible.

Though we had no specific hypotheses, we found that psychiatric diagnosis (Schizophrenia v Personality Disorder) was strongly associated with capability status. Of the ten individuals diagnosed with Schizophrenia, none was judged to be capable. This is noteworthy, because in this small sample the diagnosis of Schizophrenia was independent of level of Mental Retardation: five persons diagnosed with Schizophrenia were diagnosed with Mild Mental Retardation and five were diagnosed with Moderate Mental Retardation. The diagnostic category of Personality Disorder was more strongly associated with level of Mental Retardation, as nine of the 11 persons in this category were diagnosed with Mild Mental Retardation. Our impression is that persons diagnosed with Schizophrenia presented greater deficits in self-expression and reasoning ability than did those diagnosed with Personality Disorders and that it is these deficits which account for the differences in capability judgements. The three individuals judged capable of consenting to sexual contact but not capable of consenting to another issue had all been judged incapable of consenting to psychotropic medication.

There are several advantages to the evaluation procedure used in this study. The SSKAT is an objective, scorable scale which can be administered in about an hour. Many individuals appeared interested in the content of the SSKAT and participated very well; others needed prompting to answer. Of the 31 individuals we evaluated, just one presented inappropriate sexual behaviors associated with the test, and these were easily managed by verbal redirection. Team review helps ensure that an individual's performance on the SSKAT is an accurate reflection of his/her sexual knowledge and promotes discussion of issues relevant to consensual ability (judgement, impulse control, prior experience, etc.) but not covered in the SSKAT. The procedure can lead to the identification of areas where someone may need training, treatment, or management. A further advantage is a documented decision regarding consensual ability which is defensible in court. Additionally, if an individual is brought into court on issues related to sexual conduct, it may be advantageous to have performed this kind of evaluation as a routine part of that person's care and treatment rather than being required to perform it within the context of a legal proceeding.

One weakness of the SSKAT is that it does not have any questions relating directly to HIV infection. The examiner can easily introduce such questions into the evaluation, however. Another drawback is that the SSKAT is not

normed so it is not possible to know how much knowledge an individual demonstrates in relation to a group of his/her peers. A further drawback is that the SSKAT has many questions not directly relevant to the issue of consensual ability. If a brief screen is desired, the subset of questions referenced in Table 2 might be helpful. Administration of these items takes 15 to 25 minutes and the subset is generally highly correlated with total SSKAT scores.

Because there are no recognized standards in the field it is difficult to assess the validity of the final capability determinations based on our procedure. One way to approach the validity issue is to examine the qualifications of those making the judgements and the context in which they were made. In the present study, the team was composed of direct care and professional staff with extensive experience in the fields of mental retardation, mental health, and/or health care and with detailed knowledge of the people they were evaluating. The team made its judgements in compliance with regulatory requirements and following general guidelines of state law as part of the ongoing care provided to individuals served in their setting. The major purpose of the team's evaluations was to determine, for purposes of treatment planning, each individual's consensual ability with regard to sexual contact. It is essential to have this information, because sexual contact where one or both people involved lack consensual ability could be a crime. While the team works to enhance the self-expression and quality of life (including interpersonal relationships) of the individuals it serves, it must protect them from harm and this, obviously, includes helping them avoid illegal activities. Federal legal cases (18) support the view that the judgements of qualified professionals regarding reasonable care and treatment are presumptively valid. This means (19) that courts rely heavily on professional standards of judgement when deciding cases regarding the activities a client engages in or is trained for. Because there are no clear, professional standards for judging ability to consent to sexual contact, the second purpose of the team's evaluations was to begin to build a data base from which some guidelines could evolve. Further studies relating the outcomes of various methods of judging consensual ability to relevant variables are needed to build this data base.

In New York State 17 is the age at which individuals are considered capable of consenting to sexual contact. As a result, the treatment team often considered how a client's understanding of sexual contact, its nature, possible outcomes, and social/moral context compared with that of a 17-year old who had never had a sex education course. Such a person is presumed capable: it is rare that anyone seeks to limit his/her freedom of sexual expression based on lack of consensual ability. In making judgements, team members, drawing on their personal knowledge of local standards, tried not to apply a higher standard to individuals served than many people living in the community and presumed capable would be able to meet. It would be useful to have normative data on

what people know about sexuality. This would provide needed guidelines regarding the knowledge standards to apply in making capability determinations.

Working within New York State guidelines (2), the team's task was to make global determinations of consensual ability, but discussions sometimes focussed on highly specific situations. One individual, for example, was known to be impotent, but, for over five years, had maintained a stable relationship with a woman which included sexual contact other than intercourse (e.g., kissing, necking, petting). This man obtained a Social Age of 6.2 years on the Woodcock Johnson and had the lowest score on the SSKAT (82%) of any individual judged capable of giving informed consent. The team reasoned that because intercourse was probably not going to occur, the risks of pregnancy and venereal disease were low. Furthermore, because both parties had known and liked each other for a long time, the likelihood of victimization was minimal. This being so, the man was judged capable of giving informed consent to sexual contact with the qualification that the contact would not include intercourse and with the expectation that the man's sexual contact would continue to occur exclusively with the same woman.

As this man's case illustrates, some forms of sexual contact are less risky than others and some contexts are less complex than others. If the risks and complexity are reduced, those responsible for determining a person's consensual ability might modify their judgmental criteria accordingly. Specific, rather than general, determinations of capability are the rule in other domains. For example, a person may be judged capable of consenting to having a wart removed but incapable of consenting to open heart surgery. Or, one may be judged capable of managing spending money for the week but not of managing a substantial inheritance. Bonnie (20) argues that, in a legal proceeding, the competency to make decisions is highly contextual. A person may be competent to make one decision but incapable of making another, even within the same proceeding. This "situational competency," as Bonnie calls it, allows the argument that an individual may be capable of consenting to some forms of sexual contact with a certain individual in a particular setting but not to other forms of sexual contact with the same, or other, individuals in other settings.

Clearly, the issue of determining one's capability to consent to sexual activity is a difficult one. A major issue is that once a person is deemed incapable of consenting, his/her opportunities for sexual expression become very limited due to the global nature of the determination. The idea of situational capability is one way of addressing this as it has the potential of striking a balance between the philosophical aim of enhancing individual self-expression while allowing treatment providers to ensure that the individuals served are not being exposed to undue risk. Another way of addressing this is to examine Kaeser's (21) notion. He argues that if individuals with severe intellectual handicaps show by their behavior that they wish to engage in certain forms of sexual

contact, and if the treatment team judges that this contact can improve the quality of the individuals' lives, then third party consent should be sought, the same as it is in other matters judged to be in a person's best interest.

The assessment of consensual ability is a complex matter, where much research and discussion is needed. It is especially important for people working in the field of Mental Retardation to take the initiative, because it is individuals with Mental Retardation, especially those with Mild Mental Retardation, whose consensual ability is most likely to be in doubt.

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