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ESTABLISHING VALIDITY IN THE SOCIAL SEXUAL
AWARENESS SCALE FOR ADULTS WITH
DEVELOPMENTAL DISABILITY

By
Pauline N. Stuempfle

A Thesis

Submitted in partial fulfillment of the requirements of the
Master of Arts Degree
Of
The Graduate School
At
Rowan University
May, 2000

Approved by

Professor

Date Approved 5/2/00

ABSTRACT

Pauline N. Stuempfle
Establishing Validity in the Social Sexual
Awareness Scale For Adults with
Developmental Disability
2000
Dr. Klanderma
School Psychology

The present study seeks to establish data supporting convergent and concurrent validity of the Social Sexual Awareness Scale by correlating SSAS score with current status regarding competency to make the decision to engage in high risk sexual behavior as agreed by the IDT. The premise is that capacity to consent to high risk sexual behavior can be measured in a way that would enhance the decision making process of the court without detracting from its authority.

Archival data relating to IQ, adaptive functioning level, guardianship status, absence or presence of a secondary psychiatric diagnosis and previous IDT decisions as to ability to consent to high risk sexual behavior were collected for 51 adult male residents of a developmental center located in southern New Jersey. These data were correlated to the subjects' scores obtained on the Social Sexual Awareness Scale using a Pearson Product-Moment procedure. The data support the validity of the scale.

MINI-ABSTRACT

Pauline N. Stuempfle
Establishing Validity in the Social Sexual
Awareness Scale For Adults with
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Dr. Klanderman
School Psychology

The study seeks to support convergent and concurrent validity of the Social Sexual Awareness Scale to measure capacity to consent to high-risk sexual behavior. The scale is used to determine capacity of developmentally disabled individuals to consent to high-risk sexual behavior and is intended for both clinical and judicial purposes. Validity of the scale is supported by the data.

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Mila Vergara, Dr. Peter Finley, and Robert Hawkins for their constant encouragement and support in my academic efforts.

DEDICATION

This thesis work is dedicated to my husband, Dennis, and to my children, Justin and Aubrey without whose cooperation, encouragement and support it could not have been accomplished. Thank you for the love and patience that kept me going during this entire project.

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CHAPTER I - INTRODUCTION

Need

Increasingly, Americans in general and the courts and service providers in particular are realizing their responsibility to provide for and protect the rights of all individuals in the society, including those of the developmentally disabled population. The Americans with Disabilities Act, passed in 1990, clarified that there are no “second class” citizens and that every citizen, no matter how disabled will be afforded the rights and privileges guaranteed in the Constitution. The law even went so far as to require that accommodations be made whenever necessary in order that the disabled individual have equal access and exercise of his/her rights. In the case of the developmentally disabled population, conferring rights must be tempered with consideration for protection both of the individual and of other members of society.

Protection, unlike most other accommodations for disabled individuals, is two directional. The developmentally disabled individual must be protected from the results of unwise or otherwise inappropriate decisions she/he may make as well as be protected from the actions of others who may seek to take advantage of their disability. At the same time, the courts and service providers seek to protect the rights of the developmentally disabled individual to make decisions for him/herself -- just as any other individual would. Thus, the courts and treatment teams are constantly walking the line between protecting rights and protecting persons from the inability to practice adequate judgment to protect themselves.

The right to sexual expression is considered one of the most basic of all human rights. Indeed, sexuality and sexual expression has been known to manifest in even the most profoundly retarded of the developmentally disabled population. Sexual behavior, therefore, does not appear to be linked to IQ or to functioning level. Sexual knowledge,

however, does appear to be linked to IQ and to intellectual and adaptive functioning levels (Armstrong, unpublished dissertation, 1999). Sexual behavior which results in injury is commonly held, both by interdisciplinary teams (IDT) and the courts, not to be in the best interest of the individual. Sexual behavior involving another individual is considered high-risk behavior as it can result in a wide range of potentially negative consequences including pregnancy, disease and emotional pain and confusion. When two persons who are both developmentally disabled engage in high-risk sexual behavior and neither uses overt force, service providers rely on a clinical assessment of capacity to consent (Ames, 1991; Sundram & Stavis, 1993; Sundram & Stavis, 1994). The clinical assessment is based on the experience of clinicians and other staff working with the individuals in question and how capacity to consent is conceptualized (Valenti-Hein & Dura, 1996).

Purpose

Bogacki (1995) has designed a scale that seeks to measure the social sexual awareness of a developmentally disabled individual. The Social Sexual Awareness Scale (SSAS) was developed with consideration for both the needs of the court in defining a legal criteria for competency decisions and those of the IDT to quantify and make clinical recommendations for competency. The SSAS has been tested for convergent and concurrent criterion validity by Ms. D. Armstrong in her unpublished dissertation dated September, 1999. In that study, Ms. Armstrong correlated SSAS score with IQ score, level of adaptive social functioning, level of intellectual functioning, guardianship status, level of mental retardation, the absence or presence of a secondary psychiatric diagnosis and race.

The present study seeks to establish data supporting distinguished concurrent validity of the scale by correlating SSAS score with current status regarding competency to make the decision to engage in high risk sexual behavior as agreed upon by the IDT. If data support the validity of the SSAS, it could provide the IDT and the court a quantifiable guideline for establishing competency to give consent to high-risk sexual behavior that is both easy and economical to administer. The premise is that capacity to consent to high-risk sexual behavior can be measured in a way that harmonizes conceptually with legal definitions of competency. If so, the use of SSAS would enhance the decision making process of the court without detracting from its authority.

Hypothesis

The hypothesis of this study is that there is an association between a person's designated capacity to consent to high-risk sexual behavior as agreed upon by the IDT and his/her capacity to consent to high-risk sexual behavior as measured by the SSAS. A strong statistical correlation will suggest a high degree of concurrent validity of the SSAS thus supporting its usefulness as a tool for determining competency to make decisions regarding high-risk sexual behavior in individuals with developmental disability.

Theory

Individuals who are developmentally disabled proceed through developmental milestones at different rates and sometimes in different sequences than same age peers without developmental disabilities (Edmonson, 1980; Gebhard, 1973; Kupper, 1995; Rousso, 1994; Valenti-Hein & Dura, 1996). Individuals whose IQ places them in the mild to moderately mentally retarded range tend to develop sexually at roughly the same rate as their peers with average intelligence while they lag behind their peers in

development of problem solving skills. Individuals whose IQ falls in the more severe range tend to develop sexually at a slower rate than same age peers. Given the discrepancy between sexual development and problem solving skills, the question arises at what age can an individual who is mentally retarded be construed to be sufficiently mature to make decisions and to take responsibility for her/his own high-risk sexual behavior?

Sexual knowledge and attitudes are influenced by a variety of obvious variables including: parental knowledge and attitudes, exposure to public media, educational programs offered within schools and other life experiences such as exposure to abuse (Hingsburger, 1987; Hingsburger & Griffiths, 1987; Kupper, 1995; Lumley and Miltenberger, 1997; Raymond, 1994; Rousso, 1994). In addition, some physical disabilities such as Down Syndrome, Klinefelter's Syndrome and Prader-Willi Syndrome can result in physiosexual problems (Rowe & Savage, 1987; see also Craft, 1983). Parental expectations and attitudes toward a developmentally disabled offspring may convey to the individual the idea that sexual expression is simply not an available alternative and this attitude may occur even among some parents who would welcome open discussion of sexuality with their normally developing offspring. Developmentally disabled individuals who are institutionalized are likely to have more exposure to sexually maladaptive behavior than others (Kupper, 1995; Raymond, 1994). The work environment of the institutional staff is intentionally kept free of sex roles and/or stereotyping so that learning through environmental cues is significantly limited (Hingsburger & Griffiths, 1986). Further, institutional living, by definition, limits exposure to individuals outside the institution, thus narrowing the pool of available

partners, not only for sexual activity but for any social and/or emotional relationship (Gebhard, 1973).

Sexual awareness, like much of the knowledge and skills amassed by a developmentally disabled individual, is likely to be acquired with gaps and splinters. The sex education curriculum in an IEP is less likely to address sexual knowledge directly and may concern only issues of hygiene and gender identity. In addition, the language skills of a developmentally disabled individual may leave them at a loss for the words to describe sexual anatomy and function as well as feelings, not to mention information on sexually transmitted diseases, contraception and pregnancy. Finally, a developmentally disabled individual's lack of sexual awareness may lead to misinterpretation of behaviors as sexual in nature when, in fact, they are merely carryovers from more immature developmental stages. For example, the developmentally disabled individual may have learned to enjoy touching or being touched in certain ways as a form of giving or receiving comfort; or perhaps never acquired a sense of privacy.

The current legal standard for competency involves "knowing, intelligent, and voluntary components" of the behavior. Good decisions rest on the degree to which the courts can accurately determine that a developmentally disabled person meets these three criteria in matters of high-risk sexual behavior. To make these decisions, the courts look to interdisciplinary teams and, particularly to psychologists, for accurate assessments of an individual's status on these three components. The SSAS was developed to address the need to assess developmentally disabled individuals against the courts' model of competency while, at the same time, allowing clinicians and interdisciplinary teams to retain the integrity of their own model of competency. That is, the SSAS was designed specifically to determine a level of "knowing", "intelligent" and "voluntary" as related to

high-risk sexual behavior in individuals who are mentally retarded. Use of such a scale will aide the courts as well as the IDT in making decisions regarding these individuals' ability to give consent to high risk sexual behavior.

Definitions

Mental Retardation. According to the DSM-IV, (1) Individuals with an IQ of approximately 70 or below on an individually administered IQ test; (2) with concurrent deficits or impairments in present adaptive functioning in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety; and (3) with onset before age 18 years.

Intellectual functioning is defined as the level of capacity for rational thought and reason of a developmentally disabled individual as measured on a battery of IQ scales.

Adaptive functioning is defined as the level of capacity for appropriate social behavior and functioning in everyday life, including the ability for self care. Adaptive functioning is usually measured by IQ, SQ, and information from care providers as to an individual's level of independence in various areas.

Secondary Psychiatric Diagnosis. In persons with developmental disability, The developmental disability is the presenting diagnosis; other psychiatric diagnoses that are present are secondary. Examples may include schizophrenia, mood disorders, impulse control disorders, obsessive compulsive disorders, attention disorders, etc.

High Risk Sexual Behavior is defined as ay behavior which is sexual in nature and has the potential to result in physical, emotional or psychological harm or injury to oneself or others.

Competency (Capacity) for Consent. As used here, *competency* is a legal determination made by a judge based on information provided by professionals recognized as qualified to assess the functioning level of individuals. *Capacity* is a clinical determination, based on functioning level and service providers' knowledge of the individual and his history. Clinicians can make *recommendations*, but only the court can determine capacity for consent.

Interdisciplinary Team (IDT) is defined as a treatment team of professionals from a variety of disciplines relevant to the individual case in question. In developmental centers, IDT's generally comprise a physician, nurse, psychologist, social worker, dietitian, resident living worker and team coordinator.

Sex Education is mandated for all individuals living in institutional settings. Curricula vary according to the setting and individuals served but should include

all information needed to make informed decisions regarding sexual behavior at whatever level the individual functions.

Americans with Disabilities Act was passed in 1990. It mandates all buildings and services available to the public make whatever reasonable accommodations necessary to include and provide access for disabled individuals so they may fully avail themselves of the service provided.

Assumptions

There exists a set of interrelated abilities within the developmentally disabled person which are measured by a variety of scales and assessment techniques. These scales and techniques result in accepted ways of communicating information about the individual such that practitioners of law, medicine and psychology understand each other when speaking of IQ, social quotient, level of mental retardation, psychiatric diagnosis and guardianship status. Recent research has supported the SSAS as a reliable instrument for measuring social sexual awareness in a developmentally disabled individual. In order for the scale to be useful to clinicians and courts alike, its validity must be tested against the current decision making process of IDT's. This study sets out to correlate scores on the SSAS with previous decisions by IDT's regarding the ability to engage in high risk sexual behavior.

Limitations

Previous testing of the SSAS was done with developmentally disabled men who reside in an institutional setting. Validity data are being collected in a similar population. Further testing of the scale in community based settings and among institutionalized females is necessary to establish reliability and validity in those populations thus widening its scope of usefulness. A confounding variable may prove to be the presence of a secondary psychiatric diagnosis. Individuals who are developmentally disabled and exhibit psychotic behavior, are likely to be capable of expressing knowledge and consent

only when the psychosis is in a latent state; much the same as individuals who suffer a psychosis and are of normal intelligence.

Overview

In chapter two, this researcher will review several areas of relevant literature. As noted, a judicial ruling for competency is based on components of knowing, intelligence, and voluntariness. The limitations that a developmental disability places on an individual to be able to know and understand what is happening and what its consequences are will be discussed and the impact these limitations have on the individual's capacity to consent will be explored. These limitations have somewhat different meanings for the psychologist, the health care provider and the judge. Chapter two will explore the differences and similarities in these three fields and establish the need for an assessment tool which meets the criteria of all concerned.

Chapter three will define the variables to be measured, describe the subject pool, and determine the statistical procedures to be used.

Chapter four will present statistical analyses of the findings.

Chapter five will summarize the results and present conclusions.

CHAPTER II -- RESEARCH

Sexual behavior in developmentally disabled persons

Historically, developmentally disabled persons were thought to have no rights to sexual behaviors and were treated with varying degrees of neglect and even abuse in this area. Paternalistic attitudes along with misunderstanding and fear often led to practices which included punishment, isolation and even forced sterilization (Abramson, Parker & Weisberg, 1988; Burt, 1973; Kupper, 1995). It has been found that persons with mild mental retardation vary widely in the amount of sexual knowledge they possess (Koegel & Whittemore, 1983). What information is available to them is often obtained from peers (Gebhard, 1973). Developmentally disabled individuals lack the words to describe sexual anatomy, an understanding of how their bodies function sexually, information on how to protect themselves from sexually transmitted disease (Hingsburger & Griffiths, 1986), and knowledge of contraceptives (Edmonson, McCombs, & Wish, 1979). Further, developmentally disabled individuals experience gaps in their perception or understanding of sexual behavior (Hingsburger & Moore, 1991). For example, at what point does a touch become “sexual”; what constitutes “private”?

The United States government ordered that sex education be provided to persons with mental retardation living in institutions in 1988. Service providers are now challenged to allow developmentally disabled individuals freedom of sexual expression by providing the privacy that will permit sexual expression and the education needed about safety and possible consequences of high-risk sexual behavior (Ames & Samowitz, 1995; Brett, 1997; Morris, Niederbuhl & Mahr, 1993; Sundram & Stavis, 1994).

Though individuals who are developmentally disabled have been found to be capable of engaging in sexual behavior (Edmonson, 1980; Kupper, 1995), sexual

awakening may appear later. Some developmentally disabled persons may engage in sexual behaviors that could be harmful or even dangerous to themselves or others. Other persons may display sexual behaviors which are adaptive, but exhibit a failure to bond, disinhibition, or suspended judgement in sexual encounters (Rowan, 1988).

Correlational studies have been done comparing the sexual knowledge possessed by individuals who are developmentally disabled and a host of other variables. These include parental attitudes (Rouso, 1994; Hingsburger, 1987); institutionalization (Hingsburger & Griffiths, 1986; Kupper, 1995; Raymond, 1994); IQ and adaptive behavior (Edmonson, 1980); IQ, adaptive behavior, sex and place of residence (Edmonson, McCombs, & Wish, 1979); institutional vs. noninstitutional residence, and participation in a sex education program (Robinson, Conahan & Brady, 1992).

Consensual ability was not a variable in any of the above mentioned studies.

The meaning of capacity to consent

Legally, there are multiple types of competencies including: competency to stand trial, competency to waive rights to silence and legal counsel, competency to be found guilty, competency to parent (in custody cases), competency to serve as one's own guardian, competency to consent to treatment, competency to consent to research and competency to consent to high-risk sexual behavior. Research has been done on many of these competencies in the developmentally disabled population with mixed findings. It can be stated that, in general however, the developmentally disabled population requires a unique yardstick for measurement. Grisso (1996) developed a scale for use in determining juveniles' competency to waive Miranda rights. Fulero and Everington (1995) found that the scale could not be used with developmentally disabled adults and noted that it presented particular problems for those developmentally disabled individuals

who had little or no prior experience with the criminal justice system. Abramson, Parker & Weisberg (1988) found that persons who fall in the mild range of mental retardation have the biological capacity and desire for sexual activity, and they attribute appropriate psychological significance to sexual relations. Clearly, children do not possess these attributes. Thus, service providers must not assume that educational materials or assessment tools developed for children are appropriate for the developmentally disabled population. In other words, developmentally disabled persons cannot be viewed nor can they be treated as children by the courts, service providers or society in general.

Researchers differ on their use of the word competency. Sundram and Stavis (1993) note only two valid methods for determining competency to make a decision: (1) a clinician recognized as qualified to make such a determination; and (2) a judgement based on evidence and expert opinion. The first method is known as a “clinical determination” or “clinical competency”; the second is “judicial determination”.

Clinical determination of competency

In 1974, Barbara Edmonson stated that self-direction of activities is one important component of competence. I quote, “*competence requires one to direct one’s acts appropriately through some considerable sequence of events, and through some variety of situations ... Responsible self direction implies that one chooses a probably beneficial act as against a harmful one.*” In order to do this, according to Edmonson, one must conceptualize the probable consequence of behavior.

Kennedy (1993) argued that the word “competent” should only be used following a clinical assessment that an individual could reasonably be expected to take appropriate precautions before engaging in high-risk sexual behavior. The word “competent” has been used by others to indicate that a judge, rather than a clinician, determined that the

individual possessed “*specific knowledge, and the ability to use that knowledge in decision making, and is not under undue pressure to act in a certain way*” (Grisso, 1983). In Grisso’s view, clinicians can make statements regarding an individual’s capabilities relative to others, but only the court can determine “competency”. According to Kaeser (1992), if clients are engaging in behavior that does not endanger themselves or others and does not appear to be coercive, then it is consensual. He (i.e. Kaeser) later argued for two standards of “consent”; the first to protect a developmentally disabled individual from sexual coercion and a second to protect that person’s freedom of sexual expression. Finally, the ability to stop an interactive behavior once begun if/when the individual so desires is included in some criteria for consent (Ames & Samowitz, 1995).

For some service providers consent is tied to the absence of danger, i.e. the absence of force or physical harm. For others, the persons in question must demonstrate the process of making an intelligent decision by communicating the potential consequences of the act. Still others would simply require some previous demonstration of responsible and appropriate sexual behavior (Ames & Samowitz, 1995). The ideal is to strike a balance between the need to protect an individual from harm while also protecting the right to self-determination (Morris, Niederbuhl & Mahr, 1993).

Interdisciplinary teams consist of clinical and direct care staff with experience in the field of mental retardation, mental health and/or health care who have detailed knowledge of the persons whom they serve. IDT decisions are made in compliance with regulatory requirements and following guidelines of state law as part of the ongoing care provided individuals in specific settings. Federal legal cases have supported the judgements of qualified professionals regarding reasonable care and treatment and have considered these judgements to be valid (Romeo v. Youngberg, 1980). Thus, the courts

rely heavily on professional standards of judgement when deciding cases involving developmentally disabled individuals and issues of consent or treatment.

The determination of competency of developmentally disabled individuals has been investigated in a variety of areas. Morris, Niederbuhl and Mahr (1993) used responses to “hypothetical vignettes” to determine which individuals with mild mental retardation would be considered capable of *consent to treatment*. Fulero and Everington (1995) concluded that persons with mild to moderate levels of mental retardation generally do not have the *ability to waive legal rights* based on the results of a test of the comprehension of Miranda. *Competency to stand trial* is a problematic issue for persons whose IQ is less than 60 and for those who exhibit a personality disorder along with mental retardation (Baroff, 1996). Thus, it appears that competency in these areas is related to level of mental retardation, level of intellectual functioning and presence of a secondary psychiatric diagnosis. Finally, declaration of *competence to serve as one’s own guardian* is often an issue for developmentally disabled persons and is determined by the court; however, the determination of self-guardianship is not identical with competency to consent to high-risk sexual behavior (Grisso, 1986). While guardianship status might logically be expected to bear some relationship to a measure of capacity to consent to high risk sexual behavior in this population (Sundram & Stavis, 1994); in fact, the backlog in the courts often determines a developmentally disabled individual as a self-guardian by default.

Judicial determination of competency

The standard for legal consent involves knowing, intelligent and voluntary components (Stavis, 1987). Competency to consent presumes the individual: (1) knows”, i.e. has an understanding of a body of information about the behavior; (2) is

“intelligent” about, i.e. can apply thought to evaluate the behavior in terms of risk versus benefit; and (3) behaves in a “voluntary” manner, i.e. is not forced or coerced into engaging in the behavior (Baroff, 1996; Grisso, 1996; Lidz et al., 1984; Sundram & Stavis, 1993). Morris and Niederbuhl (1993) concluded that, in general, developmentally disabled individuals are competent to consent to sexual behavior if the retardation is mild, possibly competent to consent if moderate and not competent to consent if severe.

The state’s intent when enacting legislation and criteria for determining competency to engage in sexual behavior is to protect individuals from exploitation (Abramson, Parker, & Weisberg, 1988), not to criminalize sexual activity between consenting persons with mild mental retardation (State of New Jersey v. Olivio). The standard varies from state to state. Experts seeking to evaluate 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”*, according to regulations for the State of New York (Niederbuhl and Morris (1993). In New Jersey, a developmentally disabled individual may be considered competent to consent to high-risk sexual behavior even if he/she may not comprehend possible risks. In other states, the comprehension of risk must be present for competency to be considered, while a few states go so far as to require an understanding of the moral aspects of sexual behavior (Sundram & Stravis, 1994). A review of the law indicates that the decision as to whether a person is competent to consent to high-risk sexual behavior is determined by *“application of generally accepted, relevant professional standards which include questions of personal beliefs, morals, and societal standards of conduct and behavior”* (Stavis, 1991). It must be remembered, however, that *“neither a judicial*

declaration of incompetence nor the judicial appointment of a guardian of the person nullifies the constitutional right to privacy” (Ames, 1991).

In order for the judicial criteria for consent to be met, sex education must be provided and, as noted earlier, is required by law in institutional settings. After the developmentally disabled individual has completed the educational program, her/his capacity to consent to high-risk sexual behavior may remain a concern. In 1995, Parker and Abramson wrote, *“standardized guidelines need to be developed to assist investigators in determining the ability of an individual with mental retardation to consent. This is especially true for evaluating an individual’s understanding of nature and consequences. These guidelines must also include criteria for how much knowledge must be demonstrated to meet the legal definition of consent.”*

“Situational competency” would allow that an individual may be capable of consenting to some forms of sexual contact within certain parameters but not other forms, with other individuals, and/or in other settings. This idea stems from the notion that competency to make decisions in a legal proceeding is highly contextualized (Bersoff, etal, 1997). The acceptance of the idea of situational capability appears to be growing as New Jersey courts have recently attempted to define various levels of “limited guardianship” for developmentally disabled persons.

Measuring social sexual awareness

A statistically valid scale could provide decision makers with a set of standards to apply when evaluating developmentally disabled individuals for ability to consent to sexual behavior. Such a measure could lend the confidence that following valid and recognized practices in the field can provide.

In 1983, Dollar and Billie developed the **BRAIDED** model to meet federal, state and Planned Parenthood's requirements regarding consent and treatment. In this model, individuals are able to consent if they can articulate and demonstrate decision making using the BRAIDED acronym. That is, if they can list the *Benefits*, *Risks*, and *Alternative* forms of sexuality, if they can make *Inquiries* about the topic, arrive at a *Decision*, understand the *Explanations* and if the decision can be *Documented*. However, the BRAIDED system was developed and used only to determine consent for family planning and contraceptive treatment.

The Socio-Sexual Knowledge & Attitudes Test (SSKAT) was developed between 1976 and 1980 (Murphy, Conoley, & Impara, 1994). The test is comprised of 261 items and requires at least 2 hours to administer. Pictures can be used when verbal communication is too difficult or impossible for the subject. The SSKAT was used along with a team staffing approach to evaluate all individuals living on a residential ward (Morris & Niederbuhl, 1992). The majority of individuals with mild MR were determined able to consent to sexual activity. When they were not, it was because of cognitive deficits associated with a secondary diagnosis. Individuals who fell in the moderate range of mental retardation were usually unable to consent while those who fell below the moderate range were unable to consent. Reliability of the SSKAT was tested using an item sampling procedure but the scale has not been validated as a whole. Test/retest reliabilities ranged from 76% to 91.5% and Kuder-Richardson reliabilities ranged from .53 to .83. Significant correlation was also found using the item sampling procedure between participant's levels of intellectual and adaptive functioning and level of sexual knowledge (Edmonson, McCombs, & Wish, 1979). While the instrument attempts to assess sexual knowledge as a whole, it has several shortcomings. It does not

specifically address HIV infection (Niederbuhl & Morris, 1993); it does not assess an individual's ability to exercise judgement about possible consequences of high-risk sexual behavior; and it does not distinguish between voluntary and coerced participation.

The Sexual Consent and Education Assessment (SCEA) is a 35 item scale designed to determine a developmentally disabled person's ability to consent to high-risk sexual behavior. The scale was developed by Kennedy in 1993 and consists of three subscales. The first subscale is in the form of an interview (pictures and dolls are used for subjects with communication difficulties) and is designed to elicit the subject's level of general sexual knowledge. The second utilizes a staff informant who is interviewed regarding the subject's ability to protect himself/herself, to say "no", and to make choices in non-sexual situations. The third subscale seeks to measure maladaptive sexual behavior and generates a safety rating related to the need for staff intervention; i.e. to protect the subject or others from harm related to sexual behavior. The scale has been subjected to correlations which support predictive, concurrent and convergent validity with regard to intellectual functioning, adaptive functioning, treatment team decisions regarding a subject's ability to consent to sexual activity and prior sex education. The scale's psychometric properties seem to support its continued use. However, the SCEA measures capacity to make safe choices in non-sexual contexts only and does not specifically assess decision making in sexual contexts. Developmentally disabled individuals are known to have difficulty in generalizing learning to new contexts (Craft and Craft, 1978) and it is likely that this difficulty would apply to generalizing choices in sexual situations. Further, the SCEA inquires about intercourse but does not address other forms of partnered sexual activity; thus it may not sample an adequate range of high-risk sexual behaviors. Finally, determination of capacity to consent to sexual

activity is largely based on the 22 items of the first two subscales on the SCEA and these may provide less than adequate data on which to base such a judgement.

The Social Sexual Awareness Scale (SSAS) seeks to measure the capacity to make safe choices in sexual situations for individuals with developmental disabilities. In designing the SSAS, Bogacki (1995) considered the legal construct of competency and the needs of the courts along with the emerging guidelines for interdisciplinary cooperation between psychology and the law (Grisso, 1986; Bersoff, Goodman-Delahunty, Grisso, Hans, Poythress, & Roesch, 1997). The SSAS seeks to incorporate the knowing, intelligent and voluntary components of competency (Grisso, 1986; Stanley & Guido, 1996) in determining competency to consent to high-risk sexual behavior in persons who are mentally retarded. In case law, the “knowing” component must be satisfied first, and all three components must be satisfied. In the State of New Jersey, this is the standard applied by the courts in determining a threshold for competency.

Summary

The literature suggests a need for scales which demonstrate forensic utility (Grisso, 1986) as well as assist clinicians in determining capacity to consent to high risk sexual behavior for individuals with developmental disability. In order to demonstrate forensic utility of the Social Sexual Awareness Scale, Armstrong (1999) obtained correlations between it and IQ, social quotient, level of mental retardation, psychiatric diagnosis, guardianship status and race. These variables were chosen as they reflect accepted standards in psychology, law and medicine all of which contribute to the broader social discussion of sexual behavior (Irvine, 1994). Armstrong’s (1999) data provide support for the concurrent validity, convergent criterion validity and construct validity of the SSAS.

CHAPTER III – DESIGN

Sample

The SSAS will be administered to approximately (50) adult males diagnosed with varying levels of mental retardation and currently residing in a large developmental center in Southern New Jersey. Subjects' ages range from 18 to 63 and subjects come from a variety of ethnic backgrounds including African American, Latino and White. Subjects' IQ's range from (6 to 80) and level of adaptive functioning ranges through low average, borderline, mild, moderate, severe and profound. Subjects were culled from the existing database of all individuals presently living in the developmental center and only those individuals who are known to be sexually active were included.

Social Sexual Awareness Scale

The Social Sexual Awareness Scale was developed by a doctoral level forensic psychologist. Each of the items is based on his clinical experience, a review of the relevant literature, and familiarity with case law of the State of New Jersey pertaining to sexuality in children and in persons with mental retardation. Items were designed to draw out the subjects' responses and "yes/no" items were specifically avoided as these may foster an acquiescent response set (McCabe, 1993). Five doctoral level psychologists performed a Q sort which resulted in the elimination of redundant, unclear or otherwise unnecessary or unacceptable items. The order of items follows the requirement of the court that threshold of knowledge be established prior to exploring a person's ability to use that knowledge. That is, items related to the "knowing" component appear first, followed by items related to the "intelligent" component and finally, items related to the "voluntary" component. This order is similar to that on the WAIS-R Vocabulary and Comprehension subscales and earlier items are generally less

difficult. That is, an individual who has difficulty on earlier items of sexual knowledge will have increasing difficulty on later items related to the use of that knowledge. The later items are included in the assessment according to the procedure for administration of the scale.

The 30 items in the scale are in question form and must be answered verbally by the subject. Examiner subjectivity is minimized and guidelines for expanding upon partial responses are provided through the use of explicit scoring criteria. Each item is given a value of 0 (no credit), 1 (partial credit) or 2 (full credit) and item scores are totaled to produce a single score for each subject. This scoring method is a generally accepted means of obtaining data about a subject's level of knowledge and comprehension (Wechsler, 1981). The final score is a measure of the subject's overall level of social sexual awareness and capacity to consent to high-risk sexual behavior. Due to the scoring technique, various combinations of item scores may produce the same total score. Users are cautioned to review individual item responses prior to drawing conclusions or recommendations based on the scale. Dr. Bogacki did not include cutoff scores in the criteria for scoring as the final determination of competency is understood and accepted to be the sole province of the courts (Grisso, 1986).

The scale appears to demonstrate face validity. It was designed to assess the subject's information on: 1) knowledge of high-risk sexual behavior, 2) ability to exercise judgement in performing such behaviors, and 3) willingness to take part in such behaviors. The examiner is cautioned that some subjects may respond to any given item in the way they believe the examiner desires rather than accurately reveal their knowledge, judgement or degree of willingness to participate in high-risk sexual

behavior. This may occur particularly if the subject has encountered negative responses to sexual expression in the past.

The design of the scale would lead one to the conclusion that the SSAS may give more weight to protecting an individual from the consequences of high-risk sexual behavior while the SCEA may give more weight to protecting an individual's right to engage in high-risk sexual behavior. Ultimately, what to protect is the province of the courts and the unique combination of factors in each case must be considered (Grisso, 1986).

When compared with the scales previously discussed, the SSAS ranks favorably for several reasons. The SSAS was specifically designed to address the “knowing”, “intelligent” and “voluntary” aspects of consent (Bogacki, 1995; Grisso, 1986). The SSAS is easy to use. It's shorter and can be administered in one sitting; it's contemporary and includes questions relating to AIDS'; it contains items which sample intercourse as well as a broader range of partnered sexual activity; and there are 7 items that address the capacity to make safe choices in specifically sexual situations. Finally, the SSAS contains items which seek to define the subjects' awareness of possible consequences of high-risk sexual behavior.

Individuals with severe mental retardation may possess receptive language skills which are superior to their expressive language skills (Jacobson & Mulick, 1996). The SSAS requires subjects to give verbal responses which could result in a lower score for persons whose disability impairs verbal expression (Grisso, 1986). Over reliance on measures requiring verbal expression is thought to result in misclassification of persons with developmental disability (Panek and Haack, 1979). On the other hand, measures which use pictures and dolls to test individuals with impaired verbal expression have

been shown to suggest greater capacity to consent than is actually the case (Frost & Bondy, 1994; Grisso, 1986). At any rate, the American Psychological Association has not accepted the concept of “undisclosed literacy”. Undisclosed literacy proposes that individuals who fall in the moderate to profound range of mental retardation may have an underlying and undisplayed level of intellectual function that is in the normal range (Detterman & Thompson, 1997; Jacobson & Mulick, 1996, p.431).

Methods

Initially, a search of the existing database including all adult males currently residing in the developmental center will establish a list of those individuals who are sexually active. The archival records of the resulting subject pool will be culled to determine: (1) adaptive functioning level, (2) IQ, (3) guardianship status, (4) existence of a secondary psychiatric diagnosis, and (5) IDT decision as to whether the individual is considered competent to consent to high-risk sexual behavior. The Social Sexual Awareness Scale will be administered individually to each subject in the pool.

In order to demonstrate forensic utility of the Social Sexual Awareness Scale, this researcher will obtain correlations between the SSAS score of each S and his level of adaptive functioning, IQ, absence or presence of a secondary psychiatric diagnosis, and guardianship status. In addition, correlations will be obtained between the SSAS score for each S and the IDT decision that the S exhibits the capacity to consent to high-risk sexual behavior. High correlations in this area will support the concurrent validity of the SSAS for clinical use as the IDT decision is the current yardstick for clinical judgement.

Hypotheses

There are five hypotheses which will be investigated using individual correlational procedures with each set of data.

1. There is an association between the measured level of adaptive functioning of a person with developmental disability and his capacity to consent to sexual behavior with a partner as measured by the SSAS.
2. There is an association between IQ of a person with developmental disability and his capacity to consent to sexual behavior with a partner as measured by the SSAS.
3. There is an association between the presence of a secondary psychiatric diagnosis in a person with developmental disability and his capacity to consent to sexual behavior with a partner as measured by the SSAS.
4. There is an association between the guardianship status of an individual with developmental disability and his capacity to consent to sexual behavior with a partner as measured by the SSAS.
5. There is an association between the IDT decision that a developmentally disabled individual exhibits the capacity to consent to sexual behavior with a partner and that capacity as measured by the SSAS.

Analysis

This study seeks to establish convergent and concurrent validity of the SSAS by presenting correlations between subject scores on the SSAS and the predetermined IDT decision as to that subject's competency to consent to high risk sexual behavior. The dependent variable is the subject's score on the SSAS. The independent variable is the archival record of the IDT decision that the subject (1) can or (2) cannot give consent to high-risk sexual behavior. The relationship between SSAS score and other independent variables available in the archival records will be investigated. These include each subject's adaptive functioning level and IQ as measured on one of a variety of scales

including the VSMS, WAIS-R, and Cattell. Adaptive functioning level is generally accepted to be an accurate estimate of the individual's true ability and is recognizable to professionals from the three areas of concern; namely, judges, psychologists and care providers. SSAS score also will be correlated with a weighted score reflecting the (1) presence or (2)absence of a secondary psychiatric diagnosis. The impact of a secondary psychiatric diagnosis overlaying a known developmental disability is likely to render the individual less capable of prudent decision making. This study will also examine the relationship between guardianship status and SSAS score. Logically, individuals deemed capable of self-guardianship are better able to make informed decisions than those deemed incapable. High correlations will support the convergent and concurrent criterion validity of the SSAS, thus increasing its usefulness to the courts. The Pearson Product-Moment will be used to determine the above correlations.

CHAPTER IV – RESULTS

Data summary

SSAS scores ranged from zero to 60 where 60 is a perfect score. Only one S obtained a score of 60 while 8 obtained a score of zero. Only one of the S's who obtained a score of zero had been designated by the IDT as being able to give consent to sexual behavior. The number and percentage of subjects grouped by adaptive functioning level, IQ, secondary psychiatric diagnosis, guardianship status and IDT decision are listed in table 4.1.

Levels of adaptive functioning include borderline (3 S's, 6%), mild (14 S's, 28%), moderate (11 S's, 22%), severe (11 S's, 22%), and profound (10 S's, 20%). One subject had no designated adaptive functioning level in the archival records. Fifteen S's (29%) had no secondary psychiatric diagnosis, while 36 S's (70.5%) did exhibit such a diagnosis. Seventeen subjects (34%) served as their own guardians; however, 10 of the 17 S's (19.6%) had been recommended for guardianship and their cases were in various stages of adjudication. There were 34 S's (66.6%) who had an appointed guardian.

The data were analyzed using the Pearson Product-Moment correlation procedure. Results were proposed to be significant if there was less than a 5% probability of occurrence by chance, that is, $p < .05$. A correlation at this level between the IDT decision and score on the SSAS would suggest a high degree of convergent and concurrent validity of the SSAS. Thus its usefulness as a tool for determining competency to make decisions regarding high-risk sexual activity in individuals with developmental disability would be supported. Table 4.2 presents correlations between the SSAs and adaptive functioning level, IQ, guardianship status, secondary psychiatric diagnosis and IDT decision regarding consent.

Table 4.1**Frequency for Categories of Guardianship Status, Adaptive Functioning Level, Secondary Psychiatric Diagnosis and IDT Consent Decision (N = 51)**

Variable	No. of Subjects	%of Subjects
Adaptive Functioning Level		
Borderline	3	6.0%
Mild	14	28.0%
Moderate	11	22.0%
Severe	11	22.0%
Profound	10	20.0%
Unreported	1	1.9%
Secondary Psychiatric Diagnosis		
Absent	15	29.0%
Present	36	70.5%
Guardianship Status		
Self	7	13.7%
Other	34	66.7%
Recommended / Unadjudicated	10	19.6%
IDT Consent Decision		
No	12	23.5%
Yes	39	76.0%

Table 4.2**Pearson Product-Moment Correlation Coefficients Among Variables (N = 51)**

Measure	SSAS 1	Adaptive Function 2	IQ 3	Psychiatric Diagnosis 4	Guardian Status 5	IDT 6
1. SSAS Score	--	.708**	.728**	.135	.104	.591**
2. Adaptive Function		--	.897**	.179	.001	.597**
3. IQ			--	.282*	.020	.557**
4. Guardianship Status				--		.057
5. Psychiatric Diagnosis					--	.149

*p < .05

**p < .01

SSAS and adaptive functioning level

Hypothesis one states there is an association between the measured level of adaptive functioning of a person with developmental disability and his capacity to consent to sexual behavior with a partner as measured by the SSAS. A Pearson correlation between adaptive functioning level and SSAS score was used to demonstrate a correlation between the level of adaptive social functioning and SSAS score. As anticipated, a significant positive correlation ($r = .708, p < .01$) was obtained. Data reported in table 4.2 support the hypothesis that level of adaptive functioning is associated with capacity to consent to high-risk sexual behavior. Figure 4.1 further illustrates these results.

SSAS and IQ

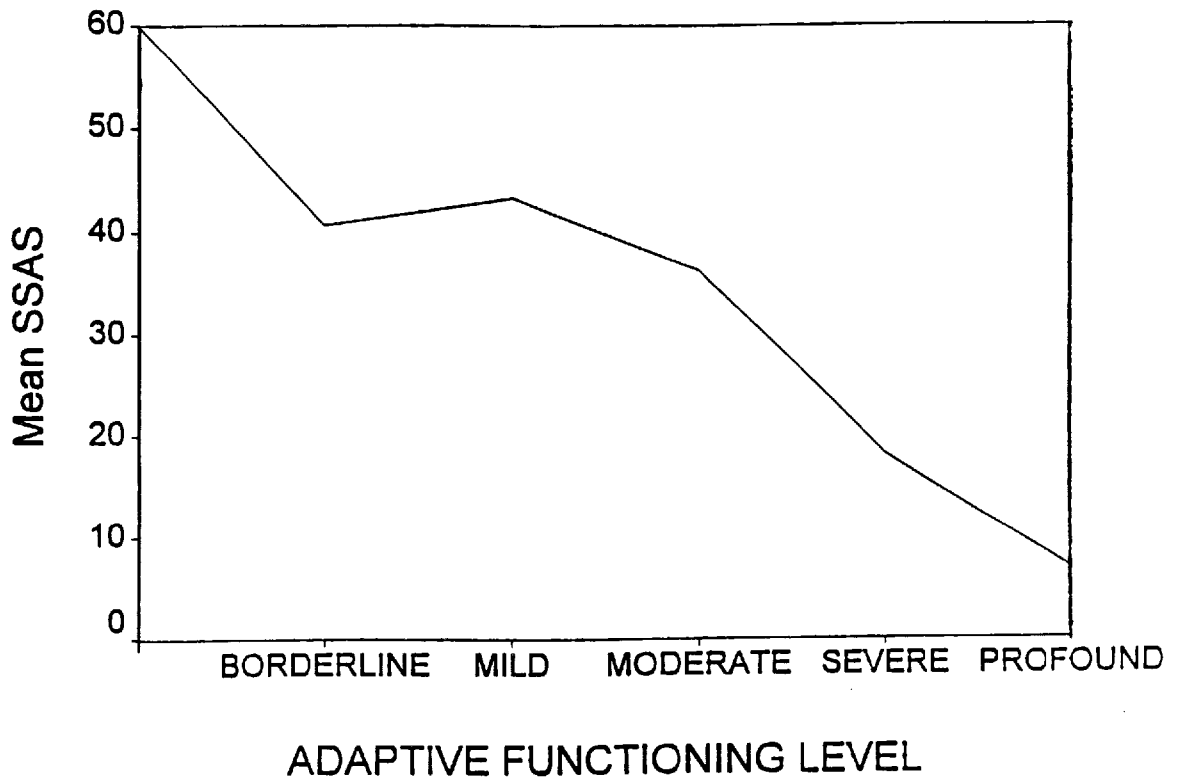
Hypothesis two states there is an association between intellectual functioning as measured by IQ of a person with developmental disability and capacity to consent to sexual behavior with a partner as measured by the SSAS. A Pearson correlation between IQ score and SSAS score was used to demonstrate a correlation. As seen in table 4.2, a significant positive correlation ($r = .728, p < .01$) was obtained which supports the hypothesis that level of intellectual functioning is associated with capacity to consent to high-risk sexual behavior

SSAS and secondary psychiatric diagnosis

Hypothesis three states there is an association between the presence of a secondary psychiatric diagnosis of a person with developmental disability and his capacity to consent to sexual behavior with a partner as measured by the SSAS. A Pearson correlation between the existence of a secondary psychiatric diagnosis and SSAS score was used to explore the relationship between the capacity to consent to high-risk

Figure 4.1

MEAN SSAS SCORE by LEVEL OF ADAPTIVE FUNCTIONING



sexual behavior and mental health. No significant correlation was obtained ($r = .135, p > .05$). (See table 4.2). It should be noted that three S's were eliminated from the data due to their psychiatric state at the time of the study.

SSAS and guardianship status

Hypothesis four states there is an association between the guardianship status of an individual with developmental disability and his capacity to consent to sexual behavior with a partner as measured by the SSAS. A Pearson correlation between guardianship status and SSAS score was used to explore the relationship between the capacity to govern oneself and SSAS score. See table 4.2. No significant correlation was obtained ($r = -.104, p > .05$). As the resulting subject pool would be too small to reveal statistical significance, data were not computed eliminating those subjects who had not yet been adjudicated but had been recommended for guardianship.

SSAS and IDT decision regarding competency to consent

Hypothesis five states there is an association between the IDT decision that a developmentally disabled individual exhibits the capacity to consent to sexual behavior with a partner and that capacity as measured by the SSAS score. A Pearson correlation between IDT decision and SSAS score was used to explore the convergent and concurrent validity of the Social Sexual Awareness Scale and is reported in table 4.2. A Pearson correlation between the IDT decision and the SSAS score ($r = .591$) does indicate a very high degree of significance ($p < .01$) and supports the usefulness of the SSAS in determining competency of developmentally disabled individuals to make decisions regarding high-risk sexual behavior.

The data were analyzed using an independent t-test to show the relationship between the IDT decision of an individual's capacity to consent to high-risk sexual

behavior and that person's social sexual awareness as measured by the Social Sexual Awareness Scale. As seen in table 4.3, for those individuals whom the IDT agreed possess the capacity to consent to high-risk sexual behavior, $M = 35.2$, $SD = 17.9$. For those whom the IDT agreed did not possess the capacity to consent to high-risk sexual behavior, $M = 7.4$, $SD = 10.9$. See also figure 4.2.

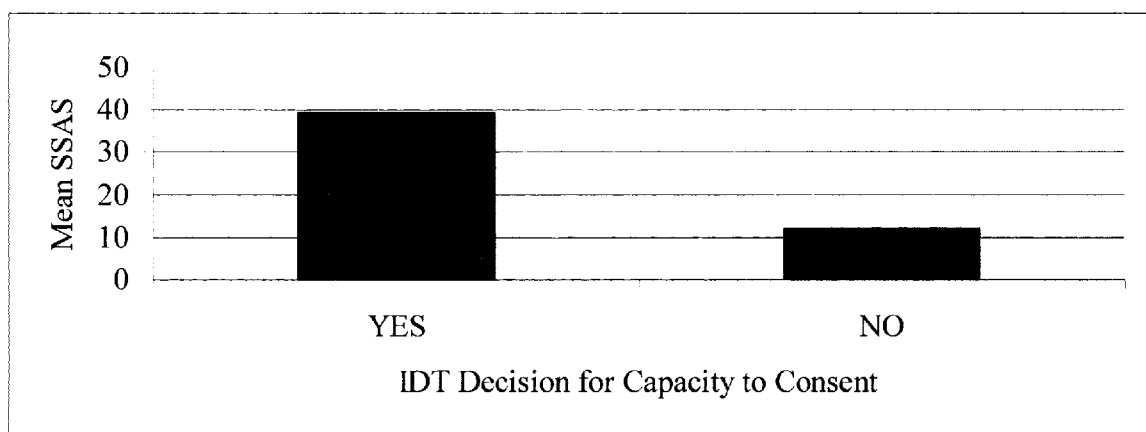
Table 4.3

Mean Social Sexual Awareness Scale Score by IDT Decision,

Variable	N	Mean	SD	t
IDT Decision				
Yes	39	35.2	17.7	2.83
No	12	7.4	10.7	3.14

Figure 4.2

Mean SSAS Score by IDT Decision for Capacity to Consent



Discriminant function analysis

As noted, three of the five variables investigated, i.e. adaptive functioning level, IQ, and IDT decision resulted in positive correlations with SSAS score. The purpose of the SSAS is to establish criteria for determining competency to consent to high-risk sexual behavior which is useful to clinicians, caretakers and the court and is economic of time and expense. In an effort to establish whether the SSAS meets the above criteria, the data were subjected to discriminant function analysis. That is, adaptive functioning level, IQ, and SSAS score data in combination were examined to determine the relationship of the combined data to IDT decision. This relationship is illustrated in table 4.4. Of the 51 S's scores, the IDT agree that 39 S's possess the capacity to consent to

Table 4.4

Discriminant Function Analysis

	IDT	Predicted Group Membership		Total
		1.00	2.00	
Original Count	1.00	30	9	39
	2.00	1	11	12
%	1.00	76.9	23.1	100.00
	2.00	8.3	91.7	100.00

80.4% of original grouped cases correctly classified.

high-risk sexual behavior and 12 S's do not. Of the 39 S's whom the IDT agreed possess capacity to consent, the combined data predicted 30 S' would possess that capacity and the remaining 9 S's would not. Of the 12 S's whom the IDT agreed do not possess capacity to consent, the combined data predicted 11 S's would not and one S would possess that capacity. Thus, Assuming the IDT decision is the yardstick for correct classification for capacity of a developmentally disabled individual to consent to high-

risk sexual behavior, the adaptive functioning level, IQ and SSAS score correctly classified 80.4% of the original group cases.

CHAPTER V – SUMMARY AND CONCLUSIONS

The present study seeks to establish data supporting convergent and concurrent validity of the Social Sexual Awareness Scale by correlating SSAS score with current status regarding competency to make the decision to engage in high risk sexual behavior as agreed by the IDT. The premise is that capacity to consent to high risk sexual behavior can be measured in a way that would enhance the decision making process of the court without detracting from its authority.

Archival data relating to IQ, adaptive functioning level, guardianship status, absence or presence of a secondary psychiatric diagnosis and previous IDT decisions as to ability to consent to high risk sexual behavior were collected for 51 adult male residents of a developmental center located in southern New Jersey. These data were correlated to the subjects' scores obtained on the Social Sexual Awareness Scale using a Pearson Product-Moment procedure.

Adaptive functioning level and IQ

As expected from the literature review, positive correlation data support the concurrent validity of the SSAS when compared to the adaptive functioning level of an individual with developmental disability and when compared to the IQ of an individual with developmental disability. Positive correlation between assessments of sexual knowledge by individuals who are developmentally disabled and adaptive functioning level and between assessments of sexual knowledge by individuals who are developmentally disabled and IQ were determined by Edmonson, McCombs, & Wish, (1979) and Edmonson, (1980). More specifically, Armstrong, (1999) reported positive correlation between social quotient developmentally disabled individuals and social sexual awareness as assessed by the Social Sexual Awareness Scale ($p = .83$) and

between IQ of developmentally disabled individuals and social sexual awareness as assessed by the Social Sexual Awareness Scale ($p = .92$).

Secondary psychiatric diagnosis

It was anticipated that the presence of a secondary psychiatric diagnosis in an individual with developmental disability would have a negative effect on that person's capacity to consent to high-risk sexual behavior. Logically, one would anticipate the presence of a secondary psychiatric diagnosis would indicate an individual's difficulty obtaining and manipulating information beyond that posed by a developmental disability alone. The compounding effect would result in the need for even greater structural supports and supervision. In fact, Armstrong, (1999) failed to show a relationship between SSAS score and presence of a secondary psychiatric diagnosis. Likewise, the data in the current study reveal no such relationship. That is, the presence of a secondary psychiatric diagnosis had no effect on SSAS score.

It is hypothesized that the range in variety and severity of psychiatric diagnoses present in the sample population proved to be a confounding variable to the study. Indeed, three S's had to be eliminated from the database due to the level of psychosis they exhibited during the period of data collection. These S's would have been able to participate in the study had data collection occurred a month earlier. This situation illustrates that, just as the court would not designate an individual incompetent based on passing cycles of psychosis, so care providers must be attuned to changing needs for protection seen in this population. Thus, no assessment of capacity to consent to high-risk sexual behavior would be valid at all times for these individuals. Instead, caregivers must base their decisions on a variety of factors including the present state of mind of these individuals. On the other hand, some psychiatric diagnoses such as impulse control

disorder or depression, for example, may not adversely affect an individual's ability to consent to high-risk sexual behavior at any time. A more cogent variable may be the current state of mind of the individual or an assessment as to his or her response to psychiatric treatment rather than the presence of a diagnosis, itself. Thus, the presence of a secondary psychiatric diagnosis poses a confounding variable that may prove interesting for future research.

Guardianship status

There was no significant correlation between the guardianship status of individuals with developmental disability and their performance on the SSAS. One might assume those S's who retain self-guardianship would present the highest correlation with social sexual awareness and capacity to consent to high-risk sexual behavior. Indeed, Armstrong, (1999) notes significant correlation between guardianship status and SSAS score in her unpublished doctoral dissertation. However, the large percentage of S's in this subject pool had been designated by the IDT as needing guardianship but not yet adjudicated appears to present a confounding variable. In order to present any meaningful data, the level of guardianship status only for those individuals who have completed the adjudication process should be correlated to SSAS scores. In the present study, the resulting subject pool would be reduced to the point where any correlation would be meaningless.

IDT decision

The data indicate a very high correlation between performance on the SSAS and the previous IDT decision as to a developmentally disabled individual's competency to consent. This finding supports the use of the SSAS for determining capacity to consent to high-risk sexual behavior. Thus, the present study supports the convergent and

distinct validity of the Social Sexual Awareness Scale as was seen in Armstrong, (1999).

Discussion

The ability to consent to a variety of areas, including consent to treatment, (Morris, Niederbuhl and Mahr, 1993); to waive Miranda rights, (Fulero and Everington, 1995); and to stand trial, (Baroff, 1996), has been extended to mean the individual also has the capacity to consent to high-risk sexual behaviors. As noted earlier, it does not follow that, for the developmentally disabled population, the capacity to consent in one area of life will generalize to the capacity to consent in other areas. The only study identified which attempts to measure capacity of developmentally disabled individuals to consent to high-risk sexual behavior as defined in this paper was an unpublished dissertation by Armstrong, (1999).

Competency to consent to high-risk sexual behavior can be measured against both legal and clinical definitions. Traditionally, the courts have relied on reports and testimony from professionals who make up the interdisciplinary teams. The legal definition includes components of "knowing", "intelligence", and "voluntary" and challenges professionals to find ways to determine, not only the presence of these components within an individual, but their degree as well. The clinical definition, on the other hand, relies on a variety of data including individually administered IQ tests, clinical observation and experience and historical documentation. Clinicians demand that any measure of capacity to consent be statistically validated to support its usefulness in the determination process. The SSAS appears to meet the needs both of the courts and of the clinicians. Unlike other instruments, it is easy, quick and economical to administer. The SSAS is designed to elicit the "knowing" component first followed by the

“intelligence” and the “voluntary” components. Concepts are presented in ascending order of difficulty and clarification of responses is encouraged. Thus, the scale appears to be useful for determining capacity to consent to high-risk sexual behavior for individuals who are verbal. It would appear particularly useful in those situations where such a determination is needed without access to archival records or caregivers acquainted with the individual. In cases where archival records and acquainted staff are available, the SSAS could serve to verify the findings of the IDT and/or to supplant them when time is a factor.

Limitations

As indicated by the research, use of the SSAS in individuals who are non-verbal is not recommended. In the present study, there were 10 S's who fell into the profound range of adaptive functioning, 8 of whom obtained a SSAS score of zero. All but one of the 8 had been designated by the IDT as having the capacity to consent to high-risk sexual behavior. None of those 8 S's would have been so designated by virtue of their score on the SSAS alone.

Given the high correlations between SSAS score and IQ and between SSAS score and adaptive functioning level, some may suggest that the SSAS is essentially measuring IQ or adaptive functioning level. However, the data do not indicate a one to one correlation. That is, as IQ went up, SSAS score tended to go up, but S's with the highest IQ did not necessarily achieve the highest SSAS score.

The SSAS lists two questions specifically referring to “venereal disease”. These questions were confusing to the subjects and had to be clarified using the term “sexually transmitted disease” or “STD's”. Revisions of the scale should reflect the more recognizable term.

This study may have been limited by sample size. The sample was chosen for its availability. It appears adequate to detect large effect sizes, such as correlations with level of adaptive functioning and IQ. However, it may have been less than adequate to detect relationships of medium effect size with other variables.

This study does not purport to consider possible differences in social sexual awareness or performance on the SSAS due to other variables. Age and social maturation continue throughout life and may impact capacity to consent to high-risk sexual behavior across the life span. Life long institutionalization of some subjects may impact capacity to consent to high-risk sexual behavior. The presence of past sexual abuse was not assessed in this study and it is not clear to what extent a history of sexual trauma may have impacted a person's performance on the Social Sexual Awareness Scale.

Conclusions

This study investigated IQ, level of adaptive functioning, guardianship status, presence of a secondary psychiatric diagnosis and IDT decision as to capacity to consent to high-risk sexual behavior in adult males with developmental disability. The Social Sexual Awareness Scale (SSAS) was used to measure capacity to consent to high-risk sexual behavior. As expected, the SSAS correlated positively with IQ, level of adaptive functioning and IDT decision. Persons with mild to moderate mental retardation performed better on the SSAS than persons with severe to profound mental retardation. Persons whom the IDT agreed possess the capacity to consent to high-risk sexual behavior performed better on the SSAS than persons whom the IDT agreed did not possess that capacity. These findings are congruent with the conceptual basis underlying the construction of the SSAS and argue for the convergent and distinguished concurrent

criterion validity of the scale. Thus, the use of the SSAS as a quantifiable guideline for establishing competency to consent to high-risk sexual behavior was supported. It appears from the present study that the SSAS approaches the "*standardized guidelines (that) need to be developed*" (to enhance the decision making process of the court. (Parker and Abramson, 1995).

Implications for future research

Further study on the SSAS should include reliability and generalizability. Reliability may be established by administering a test and retest. If so, it may be important to consider that sex education may occur between test sessions which would influence a S's performance on the scale. Reliability could also be demonstrated by showing scoring agreement among two or more raters. The entire scale or selected items may also be useful as a pretest and post-test by persons providing sex education.

In revising the scale for use by female subjects, it is necessary to include additional items assessing awareness of the possibility of pregnancy. Also, items assessing knowledge of contraception beyond the use of a condom would be helpful. Such modification would require permission from the author to make changes in his work. The impact on validity and reliability of the original scale would also need to be assessed subsequent to any modifications.

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APPENDIX A

SCORING CRITERIA AND SAMPLE ANSWERS:
SOCIAL SEXUAL AWARENESS SCALE

SCORING:

Ask the client each question in a discussion-type format. After discussion, score the client's response as 2, 1 or zero. Responses are scored as 2, 1 or zero depending on the degree of generalization and their quality. A 2-point response is consistent with clear awareness or knowledge about the question. A 1-point response is consistent with a minimum threshold of understanding, but less well understood than a 2-point response. A response scored zero would be consistent with a lack of knowledge, incorrect information, or irrational judgments about the questions. Poor verbalization should not be penalized. For example, a satisfactory 2-point response may be badly worded. Where it is indicated that a response should be questioned, as shown by a (capital letter Q), the reply to the questioning should be evaluated according to the stated criteria listed below.

For every item in the scale, the general criterion for each level of credit is shown followed by some typical answers.

1. WHAT DO PEOPLE DO WHEN THEY HAVE SEX?

2 points- Any response which gives examples of people engaging in sexual activity.

"I put my thing in his mouth.....". "He put his thing in my butt.....": Any responses indicating mutual masturbation or fondling.

1-point response- "They sleep together" (Q).....
"He does bad things to someone" (Q).....

Zero points-responses not including reference to sexual interaction.

"People do sex when they have a headache....."
"I don't know". "They have fun"(Q)....."

2. WHAT IS VENEREAL DISEASE OR VD?

2 points- A response showing knowledge regarding venereal disease.

"It is something you can get from having sex....".
"You can get sick and have to have needles from having sex".

1 point- Responses less general than above.

"It makes you sick (Q)....."

"It's bad for you....."

"You usually get the clap (Q)....."

Zero points- Response not including reference to venereal disease or sickness.

"It's a football team....."
"..... I don't know".

3. HOW DO YOU GET VENEREAL DISEASE - VD?

2 points- Any response which reflects information about having sex with an infected person.

"You get it from having sex with somebody else who has it....."

"You get it by having sex without wearing a condom".

1 point- responses reflecting minimal threshold of understanding but less well understood than above.

"Having sex (Q)"...

"Through their penis" (or vagina) (Q).

Zero points- No idea of how venereal is contracted.

4. HOW CAN YOU KEEP FROM GETTING SEXUAL DISEASES?

2 points- Any response containing the idea that sexual diseases are contracted from unprotected sexual activity.

2 points- Recognition that preventing of sexual diseases can be prevented from abstinence, use of protection. Any response that articulates hygienic or pertinent medical factors.

"Make sure you don't have sex with someone who has VD or AIDS.....". "Make sure that you use protection if you have sex....." "Use protection (Q)".

1 point- Recognition that sexual behavior potentially produces sexual diseases.

"You could get it if you have sex....." "Try to make sure everything's clean (Q)".

Zero points - No idea of what to do regarding the prevention of sexual disease.

5. WHAT IS AIDS?

2 points- Any response containing the idea that AIDS is a sexually acquired disease that requires the exchange of bodily fluids.

"You will get it if you have anal sex without a condom". "You can get it if you have oral sex without a condom."

1 point - Recognition that AIDS is a sexually transmitted disease.

"You can get it from having sex". "You can catch it from somebody if you have sex".

Zero points - Response which does not indicate awareness that AIDS is a sexually transmitted disease.

6. HOW DO YOU GET AIDS?

Recognition that AIDS is acquired through sexual contact with an infected person.

2 point - "You can get it from having sex with somebody else who has AIDS...". "You can get it from having sex with someone who has contracted the AIDS virus."

1 -point - "You can get it from having sex (Q)".

Zero points - No idea that AIDS is a sexually transmitted disease.

7. WHAT CAN YOU DO KEEP FROM GETTING AIDS?

2 points- Any response recognizing that AIDS can be prevented through responsible sexual behavior.

"You can use a condom..."

1 point - "Don't have sex".

Zero points - "You can only have sex once in a while if you think they have AIDS".

8. WHAT IS A CONDOM?

Recognition that a condom is something used to prevent sexually transmitted disease.

2 point response - "It's s rubber used when you have sex".

1 point - "It's a thing you put over your private part (Q)"

Zero points - "A large bird found in California...".
No answer.

9. HOW DO YOU USE IT?

2 point response - Any explanation of appropriate use of a condom.

2 point response - "Put it over your penis...".

1 point - "You put it on (Q)....".

Zero points - "You take it out of the packet and swallow it before sex".... No response.

10. WHAT DO YOU DO WITH A USED CONDOM?

2 point - Recognition that a used condom should be disposed of in an appropriate area.

2 point - "Flush it down the toilet...". "Throw it in the trash".

1 point - "You can wash it out and use it again".

Zero points - No awareness detected for appropriate disposal.

11. WHERE CAN YOU GET CONDOMS?

Awareness that condoms can be obtained from the nurse or asking WDC staff.

2 points - "You can ask the nurse..." "You can ask your group leader....".

1 point - "You can buy them at the Galley....".
"You can find one sometimes in other people's rooms".

Zero point - No recognition as to where to obtain condoms.

12. HOW OLD DOES YOUR FRIEND HAVE TO BE TO HAVE SEX WITH YOU?

Awareness that sexual partners must be age 18.

2 point response - "He/she must be 18 years or older."

1 point response - "Ask them how old they are."

Zero points - "Just do it when you feel like it...."

13. WHAT HYGIENE IS GOOD TO PRACTICE BEFORE SEX?

Recognition that appropriate hygiene is beneficial to practice prior to sex.

2 point- "You should get a shower...." "You could clean up before sex."

1 point response - "Go to the bathroom before....."
"Get into bed"

Zero points - No recognition of hygiene prior to sex.

14. WHAT HYGIENE IS GOOD TO PRACTICE AFTER SEX?

Recognition that appropriate hygiene will reduce risk factors for disease and specifically sexually transmitted disease after partners engage in sex.

2 points - "Get a shower (or wash up) after sex..."
"Clean up when you are finished"

1 point - "Go to the bathroom"

Zero points - No recognition that hygiene is important after sex.

15. WHAT DOES ORAL SEX MEAN?

Recognition of oral genital contact.

2 points - "You put his penis in your mouth".

Zero points - A lack of understanding of the meaning of oral sex.

16. WHAT DOES ANAL SEX MEAN?

Recognition that anal sex refers to anal/genital contact.

2 points - "You put your penis in his behind"

Zero points - No recognition of what the term anal sex refers to.

17. WHY DO PEOPLE HAVE SEX?

Recognition that people have sex for procreation, they have emotional feelings toward one another, and that sex is a form of physical relief.

2 point answer - "Because it feels good...." .
"Because you can make babies that way."

1 point response - Because I saw another client doing it....". "Because I like to".

Zero point response - No response as to why people interact sexually.

18. WHO CAN YOU HAVE SEX WITH?

Recognition that the partners need to be over the age of 18 and are willing partners.

2 points - "You can have it with someone who wants to have sex and is over 18".

1 point - "They said Yes....." "he said he wanted to do it" (Q)

Zero points - No recognition of consent.

19. WHEN IT IS ALRIGHT TO HAVE SEX?

Recognition that sexual behavior should occur in a private place and at appropriate times.

2 points - "You can do it in your room at nighttime".

1 point - "You can do it when nobody is looking".
(Q)

Zero points - No recognition as to context or environment in which to have sex.

20. WHEN IS IT NOT ALRIGHT TO HAVE SEX?

Any response containing the idea that the social context or the environment may be contraindicated for sexual behavior.

2 point - "When you are in a public place....."
"When the other person doesn't want to do it".

1 point - "Time for meals"

Zero points - No recognition as to inappropriate context or environment.

21. WHERE CAN YOU HAVE SEX?

Recognition that sexual behavior should occur in an appropriate place.

2 point response - "You can have it in your bedroom"

1 point response - "You can have it in the bathroom". "You can have it in the day room".

Zero point response - "You can have it wherever you want.....". No response.

22. WHERE CAN'T YOUR HAVE SEX?

Recognition that certain environments are prohibited.

2 points - "You can't do it at the Galley". "You can't do it at work....."

1 point response - "You can't do it whenever somebody can see you". (Q)

Zero points - No recognition that specific environments prohibit sexual behavior.

23. WHAT KIND OF FEELINGS DO YOU HAVE FOR SOMEONE YOU HAVE SEX WITH?

Recognition of a client's emotional feelings toward a sexual partner.

2 points - "You can do it with somebody who you like a lot.....". "They make me feel horny (or aroused)".

1 point response - "You can do it with somebody you don't hate"

Zero points - No recognition of feeling state associated with sexual behavior.

24. HOW CAN SOMEONE GET HURT PHYSICALLY FROM HAVING SEX?

Recognition that sexual behavior can cause physical injury.

2 point - "You can bruise them or hurt them....". "You could get bit".

1 point - "You could fall off the bed".

Zero points - No recognition of physical harm from having sex.

25. HOW CAN SOMEONE GET HURT EMOTIONALLY FROM HAVING SEX?

Recognition that sexual behavior may cause arousal of emotional feelings in sexual partners.

2 point - "If your partner (friend) might make me mad if he did it with somebody else....." "If you just did it once, you didn't care about the person, they might get hurt"

1 point- "They may cry if you do it to them".

Zero points- No recognition of relationship between emotional state and sexual behavior.

26. HOW DO YOU KNOW WHEN YOUR PARTNER DOESN'T WANT TO HAVE SEX?

Recognition that sexual partners give verbal and nonverbal cues when they do not want to have sex.

2 point response - "They say no or walk away from you".

1 point response - "When he says no, sometimes he wants to do it anyway".

Zero points - No recognition that partners give behavioral cues when they do not want to have sex.

27. WHAT SHOULD YOU DO IF YOU DON'T WANT TO HAVE SEX AND YOUR FRIEND DOES?

Recognition of giving verbal and physical prompts to prevent sexual behavior from occurring.

2 points - "Tell him No....". "Stay away from him when you don't want to do it".

1 point - "Say Okay, but just this once?"

Zero points - No recognition as to how to communicate lack of interest in sexual behavior.

28. WHAT SHOULD YOU DO IF YOU ARE BEING FORCED TO HAVE SEX?

Any response containing the idea that steps should be taken to elicit the help of others to prevent forced sex.

2 points - "Yell for help.....". "Yell for your group leader to help you".

1 point response - "Just cry (Q)".

zero points- No recognition of how to ask for assistance.

29. WHO DO YOU TELL WHEN SOMEONE FORCES YOU TO HAVE SEX?

Recognition that staff should immediately be notified if sexual relations are forced upon the client.

2 points - "Tell your group leader.....". "Tell the HPC"

1 point - "Tell your roommate what happened"

Zero point - No recognition of whom to report forced incidents of sex.

30. HOW DO YOU KNOW THAT YOUR FRIEND MAY NOT WANT TO HAVE SEX, EVEN THOUGH HE MAY HAVE SAID YES?

Recognition that consent (may be coerced by pressuring someone into sex).

2 points - "When he lets me do it but it doesn't really look like he wants to....." "When he says no several times but still says he will do it".

1 point - "He asks for money, but doesn't really seem like he wants to do it".

Zero point - No recognition. No response.

APPENDIX B



State of New Jersey
DEPARTMENT OF HUMAN SERVICES
DIVISION OF DEVELOPMENTAL DISABILITIES

PO Box 726
TRENTON NJ 08625-0726

CHRISTINE TODD WHITMAN
Governor

MICHELE K. GUHL
Commissioner
DEBORAH TRUB WEHRLER
Director
TEL. (609) 292-3742

January 5, 2000

Pauline N. Stuempfle
1028 Terns Landing Rd.
Pittsgrove, NJ 08318

Dear Ms. Stuempfle:

I am writing to approve your request to conduct research for your master's thesis in Psychology at Rowan University, studying the relationship of scores on the Social Sexual Awareness Scale and IDT decisions as to the ability of individuals living at the Woodbine Developmental Center to consent to sexual behavior. Dr. Holloway, The Division's Research Director, has indicated that the staff at the developmental center will be providing you with the information you need in a coded format, so that you will never have to review consumer records.

I am happy we are able to do this for you, but should the staff find this to be too demanding of their time, you will have to use the normal procedure required for gaining access to client records as defined in Division Circular #30.

I hope you are successful with this project. Please keep us informed of your results. If you should have any further questions, please contact Dr. Holloway at 609-984-5379.

Sincerely,

Deborah Trub Wehrlen
Deborah Trub Wehrlen
Director

cc: File
R. Armstrong
R. Lowe
W. Holloway