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Introduction

1 Chapter

Description of the Socio-Sexual Knowledge and Attitudes Assessment Tool-Revised (SSKAAT-R)

The SSKAAT-R was designed to assist educators and clinicians working with persons with developmental disabilities. It evaluates information persons with developmental disabilities have about their bodies, socio-sexual intimacy, relationships and issues of abuse.

The SSKAAT-R was developed to:

- Determine the knowledge and attitudes of people with developmental disabilities with regard to socio-sexual information
- Serve as a baseline and an educational aid when developing person-centered socio-sexual curricula
- Provide a means of evaluating socio-sexual training effectiveness
- Aid in evaluation research
- Serve as one aspect of a comprehensive assessment for individuals who may be experiencing socio-sexual challenges

It is important to note that SSKAAT-R is not designed to be predictive or diagnostic when used as an isolated tool. It assists clinicians in uncovering information to be used in conjunction with other clinical interview and assessment strategies.

Check your materials. Your SSKAAT-R Kit should include:

- Manual
- Easel Book
- 6 Laminated 8" x11" Cards
- Record Forms, Pk/20

Rationale for the Socio-Sexual Knowledge and Attitudes Assessment Tool–Revised

Change in Priorities in Past 20 Years

In 1979, the Socio-Sexual Knowledge and Attitude Test (SSKAT) was developed by Joel Wish, Katherine Fiechtl McCombs and Barbara Edmonson. The SSKAT was based on research carried out in the 1970s with men and women with developmental disabilities, living in institutions, and in the community. Its content was determined by surveying parents, educators, institutional and community based clinicians regarding the importance of various areas for testing and education. Their results, published in the SSKAT Manual, indicated that the most important areas for sex education were birth control information, intercourse, venereal disease (how to catch, symptoms and who to tell), and pregnancy (how to get and prevent). Avoiding street pick-ups and inappropriate physical contact were also ranked as very important. Identification of body parts and dating were also considered important.

More than 20 years have passed since the development of the SSKAT. Griffiths & Lunsky (2000) replicated the survey and found there had been subtle, but important, shifts in priorities for socio-sexual assessment and education. (Described more fully in *Chapter 6: Development of the SSKAAT-R*). However, the general findings reflected a change in priority and emphasis on the socio-sexual information required in today's society.

There are many social reasons why key issues of socio-sexual knowledge of persons with developmental disabilities have changed. They include:

- Move to community living
- Growth of socio-sexual education
- Emphasis on accountability
- Awareness of abuse and exploitation
- Concern for sexual health
- Treatment for sexually inappropriate behavior
- Sensitivity toward diverse populations

The Move to Community Living

Since the SSKAT was produced in the 1970s, the field of developmental disability has experienced widespread de-institutionalization, and a return to community living. As a result, normalization of lifestyle choices and the enhancement of relationships have become cornerstones of today's service delivery system. They need to be reflected in a socio-sexual assessment of knowledge and attitudes.

Growth of Socio-Sexual Education

In the past twenty years, the field has been inundated with sexuality education programs for persons with developmental disabilities. However, sexuality education programs have generally not been evaluated (Whitehouse & McCabe, 1997). Coleman and Murphy (1980) reported that one-third of the institutions surveyed lacked evaluation of their sexuality education programs. The remaining two-thirds evaluated their programs using a variety of measures including surveys of staff reactions, pre-post questionnaires, or behavioral measures of the residents. However, 79% of the evaluation results were unavailable, rendering the reliability of the evaluation methods questionable.

People with developmental disabilities are being taught, and therefore it is assumed they have acquired, knowledge and skills about sexuality. However, there is little empirical evidence that persons with developmental disabilities acquire or retain knowledge and skills as to be utilized in their daily lives. There is little data regarding which participants will benefit most from a general sexuality education course (Lindsay et al., 1992), or if different methods of instruction are more effective with different participants. Without empirical evidence from pre- and post-training evaluation, control group comparison, and generalization data, assumptions that such knowledge has been acquired may be both erroneous and dangerous.

Emphasis on Accountability
There is an emphasis on accountability in the modern service delivery system. Agencies providing services are required to demonstrate that their programs are effective. Accountability requires:

- Evaluation of the effectiveness of programs that agencies provide
- Programs are implemented based on empirical research and demonstrated effectiveness, for the specific group, to produce improvements in both knowledge, skills and behavior. Evaluations must be conducted using tools that have been validated and shown to be reliable through research.

Importance of Evaluation
When teaching sexuality education, it is important to assess the participant's skills, before instruction, to determine where to begin with socio-sexual training (Edmonson, et al., 1979). Testing should also occur during and after the intervention as a means of evaluating progress (Lumley & Miltenberger, 1997). Minimally, Griffiths (1999) advocates the use of pre- and post-evaluation of sexual knowledge and attitudes. Although considerable clinical anecdotal evidence exists, there is little empirical support to demonstrate that persons with developmental disabilities benefit from sexuality education programs (Lindsay, Bellshaw, Culross, Staines, & Michie, 1992; Whitehouse & McCabe, 1997). For example, Whitehouse and McCabe (1997) noted, that although many studies claim to evaluate efficacy they failed to produce data to support their claim.

Value of Research
Sexuality education research has had several methodological flaws, including a lack of adequate measures, a lack of control comparisons, and limited follow-up evaluation of maintenance or generalization (Whitehouse & McCabe, 1997). Of the research that has reported evaluation data, none reported the effectiveness of sexuality education in relation to increasing sexual knowledge and enhancing positive attitudes toward sexuality (Whitehouse & McCabe, 1997). Future research could benefit from empirical validation of sexuality education assessing improved knowledge, skill generalization and maintenance, and the social validity of the training.

Awareness of Abuse and Exploitation
The field has become aware of the higher rates of abuse and exploitation of persons with developmental disabilities. Research has shown that:

- Persons with developmental disabilities are far more vulnerable to abuse than persons who are non-disabled
- Abuse is most likely perpetrated by persons known to the victim
- The abuser, often a caregiver, gains access and opportunity to abuse through the disability system (Sobsey & Doe, 1991)
- Among persons who had been provided sex education, abuse rates are considerably lower for those who have had the benefit of socio-sexual education (as cited in G. Allan Roeher, 1988)
- Sex education, therefore, may be a factor in the protection of individuals, through the prevention of boundary violation and the promotion of mental wellness

Emphasis on Sexual Health
The discovery of HIV/AIDS, and its presence in this population, has led to increased attention on sexual health. Society has experienced a critical paradigm shift regarding the value of sexuality education because of the discovery of the HIV virus. This discovery increased the risks of a lack of sexual awareness among persons with developmental disabilities. Even now, people with developmental disabilities know very little about HIV/AIDS and how to minimize their risk (McGillvray, 1999). In addition to requiring a change in sex education curriculum, this discovery has led agencies to recognize the critical importance of evaluating and documenting the effectiveness of educational programs (e.g., Jacobs, Samovitz, Levy, Levy, & Cabrera, 1992; Scotti et al., 1997). Agencies have begun to become accountable for the quality of their sexuality education (see Kastner, DeLotto, Scagnelli, & Testa, 1990). There is now an increased emphasis on

evaluation of sexuality programs to ensure that people are not just provided sexuality education, but that they acquire knowledge, are able to apply this knowledge, and feel empowered to use this knowledge where appropriate (Griffiths, 2002).

Whereas earlier sex education programs emphasized the importance of hygiene, there has also been a recent shift toward issues of health. Several papers have been written in the last five years on the lack of preventative health care for adults with developmental disabilities, including sexual health care (e.g., Beange, McElduff, & Baker, 1995; Lennox, Diggens, & Ugoni, 1997). For example, women in North America and Europe, with developmental disabilities are less likely to receive cervical screening than other women (Minihan & Dean, 1990; Pearson, Davis, Ruoff, & Dyer, 1998). Recent initiatives are focusing on preventative health including sexual health (e.g., Lunsky, Straiko, & Armstrong, 2002), and go beyond simple hygiene.

Treatment for Sexually Inappropriate Behavior
With the advent of massive de-institutionalization, and the expansion of community living for persons with developmental disabilities, the field became faced with the need to develop treatment strategies for inappropriate sexual behavior. Prior to this time, sexually indiscriminate behavior was managed by incarceration in segregated facilities. Although early behavioral intervention focused on punitive approaches to suppress these behaviors, the field has come to recognize that often, sexually-inappropriate behavior, when committed by persons with developmental disabilities, is the result of a lack of knowledge (Griffiths, Hingsburger, & Quinsey, 1989).

Recent clinical examples demonstrate that a lack of education regarding sexually appropriate and responsible behavior represents a critical vulnerability for the development of sexually inappropriate behavior (See, Griffiths, 2002). Hingsburger, Griffiths, & Quinsey (1991) presented case examples of persons with developmental disabilities for whom the treatment, for certain inappropriate sexual behaviors, was sex education alone. Other cases, however, represent more clinically-complex intervention, where sex education is often a critical vulnerability for the development of the inappropriate sexual expression, and one of the main components of effective intervention (Griffiths, et al., 1989; Griffiths, 2002).

Sensitivity to Diverse Populations
In recent years, individuals developing assessment materials have become sensitive to the need to recognize diversity. A new assessment was needed to ensure that pictures recognized physical, intellectual and ethnic diversity. Several efforts were made to include people with disabilities, and from a range of ethnic backgrounds in the photographs as well as the drawings.

Prior Socio-Sexual Assessment
The most comprehensive and widely used socio-sexual assessment to date has been the SSKAT (Socio-sexual Knowledge and Attitudes Test, Wish, McCombs, & Edmonson, 1980). It was designed to be individually administered. The use of a picture book allowed participants to answer questions, requiring extensive verbal demands. Wish et al. (1980) determined that the SSKAT provided reasonable test-retest reliability of subtest scores across subjects on knowledge, ranging from 78.2% on the homosexuality subtest to 89.7% on marriage subtest. For attitude items, average agreement was similarly high, ranging from 76.0% agreement on the intimacy subtest to 91.5% on the pregnancy, childbirth, and child rearing subtest. Validity data were not presented. However, the test was based on a content analysis study.

The SSKAT had been criticized, in recent years, because it is time consuming, requires a high level of skill to administer, is overly complicated in parts but not exhaustive in others, contains many value-laden items, and does not discuss the sexual experiences of the individual (Edmonson et al., 1979; McCabe, et al., 1999). Moreover, as Griffiths and Lunsky (2000) noted, the field has shifted in what it prioritizes as important in socio-sexual education. A content-analysis, based upon feedback from the field, indicated a need for significant change, and the inclusion of items relating to sexual health, HIV/AIDS, as well as sexual abuse and healthy boundaries (Griffiths & Lunsky, 2000).

Relationship between the SSKAAT-R and the SSKAT
The SSKAAT-R was developed through a multistage process, described fully in Chapters 6 and 7. Following is a brief outline of the process.

1. A content survey was conducted with 80 parents, educators, and institutional and community-based clinicians working with persons with developmental disabilities.

2. A focus group of individuals with developmental disabilities was surveyed, by a community agency, to validate the most important content areas.
3. Current SSKAT users were surveyed for their opinions and recommendations regarding what to keep and what to change.
4. Several of the most popular, commercially available socio-sexual education programs were analyzed for content areas.
5. The SSKAAT-R was developed, and content areas were evaluated, against the SSKAT.
6. The SSKAAT-R was field-tested across North America to assess reliability and validity.
7. Minor changes were made to the SSKAAT-R, resulting from field-tester feedback.

Differences between the SSKAT and SSKAAT-R

The SSKAAT-R is not a test, but an assessment tool. The SSKAT was described as a test, which led to a misunderstanding, due to a lack of specific norms.

Differences in Topics

Most of the topics covered in the SSKAT have been included in the SSKAAT-R, with the exception of items on alcohol and drug use and other community risks and hazards. Additional items have been added on the topics of HIV/AIDS, sexual health, menopause, age discrimination, appropriate/ inappropriate touch, and greater diversity in sexual activities. Decisions regarding what to include and exclude in the SSKAAT-R were based on feedback from experts in the field as well as users of the SSKAT (Griffiths & Lunsky, 2000). **Table 1** compares the topics in the SSKAT to the SSKAAT-R.

The SSKAT had 14 sections. They included Anatomy Terminology; Menstruation; Dating; Marriage; Intimacy; Intercourse; Pregnancy, Childbirth and Child-rearing; Birth Control; Masturbation; Homosexuality; Venereal Disease; Alcohol and Drugs; Community Risks and Hazards, and Terminology Check.

The SSKAAT-R has seven subtests. They are:

1. Anatomy
2. Women's Bodies (and women's knowledge of men's bodies)
3. Men's Bodies (and men's knowledge of women's bodies)
4. Intimacy
5. Pregnancy, Childbirth and Child Rearing
6. Birth Control and STDs
7. Healthy Socio-Sexual Boundaries

Differences in Organization

Organization of the SSKAAT-R is also different:

- Presented in a stand-up Easel fashion
- Questions, and scoring information, are included on the Easel, making it more user-friendly
- Single response-analysis sheet

SSKAAT-R photos and sketches have been updated. Sketches have been produced with minimal background sketch lines to eliminate figure-ground confusion. Photos were shot in black-and-white to reduce distracting features, and to maintain consistency between photos and sketches. Sketches are used to reflect private and intimate images; photos are used for public behaviors.

Questions have been modified, when possible, to minimize expressive language requirements. For example, instead of asking, "What is special about this woman?", the SSKAAT-R asks, "Show me the woman who is pregnant." And then, "How do you know?"

Attitude items are not scored as "correct" or "incorrect."

SSKAAT-R has reduced some redundancy found in SSKAT. For example, rather than showing six photos and asking after each one, "Is this person a good babysitter?" the examinee is now asked to select the "good babysitter" from four photos.

When introducing the difficult topics of appropriate/inappropriate touch and interaction, the SSKAAT-R uses scenarios, rather than asking general conceptual questions. For example, a picture of a man and woman sitting together on a couch is shown. The examinee is told, "Mary and John are on their second date. Mary likes John very much and wants to kiss him. Is it OK for John to kiss her?"

The SSKAAT-R uses two types of questions. **Core** questions assess general information important in all socio-sexual evaluations. **Optional** questions include practical, or advanced, questions for a more in-depth evaluation. Questions of a sensitive nature that may not be used due to cultural or religious issues, or personal sensitivities (i.e., abuse) are also considered optional.

Table 1
Comparison of SSKAAT-R to SSKAT: Content Analysis

SSKAAT-R	Areas Evaluated	Comparison to SSKAT
1. Anatomy (12 questions)	(i) discrimination of gender and age (ii) identification of body parts (iii) function of sexual body parts	Anatomy terminology is similar with exception of new items on discrimination of differences between children and adults.
2. Women's Bodies and Women's Knowledge of Men's Bodies FOR WOMEN ONLY (31 questions)	(i) privacy awareness (ii) menstruation, including practical exercise (iii) menopause (iv) female masturbation (optional) (v) erotica (optional) (vi) sexual health (vii) male erection and ejaculation	Menstruation and masturbation were covered as separate issues in SSKAT. New items on privacy, menopause, erotica and sexual health have been added.
3. Men's Bodies FOR MEN ONLY (22 Questions)	(i) ejaculation (ii) erotica (optional) (iii) male sexual health (iv) menstruation	Includes topics previously covered in masturbation section of SSKAT. Issues of privacy, erection, ejaculation, sexual health and erotica are new topics.
4. Intimacy (35 Questions)	(i) dating (ii) marriage (iii) handholding (iv) hugging (v) kissing (vi) necking (vii) naked touching (viii) sexual intercourse (ix) anal intercourse (x) oral intercourse (xi) orgasm (xii) homosexual relationships	Items included in SSKAT intimacy section have been removed and added to either pregnancy or healthy boundaries (Includes items previously covered under dating, marriage, intimacy, intercourse and homosexuality in SSKAT. However they included under intimacy issues which the new version now deals with as sexual boundary questions and pregnancy questions—see sections listed below.)
5. Pregnancy, Childbirth and Child Rearing (32 Questions)	(i) who can get pregnant/make a baby (ii) what to do if pregnant (iii) childbirth (iv) baby care (v) adoption (vi) abortion (optional) (vii) miscarriage	Included in three sections: pregnancy, childbirth and child rearing.
6. Birth Control and STDs (35 Questions)	(i) types of birth control (ii) abstinence (iii) sterilization (iv) birth control pills (v) condoms/ spermacide including optional practical exercise on condom use (vi) STD's/AIDS (vii) disease protection	This topic was in two separate SSKAT sections on birth control and venereal disease. In current version only most commonly used birth control methods included. The choice of abstinence has been added as an option. Disease information has been updated and includes AIDS and disease protection.
7. Healthy Sexual Boundaries (27 Questions)	(i) age/gender identification (ii) appropriate partners (iii) inappropriate and appropriate touch (iv) consenting touch (v) touch for money (vi) touch by staff (vii) touch by family (viii) public and private behavior (ix) age inappropriate interaction (x) forced sexual contact (xi) reporting unwanted sexual contact/ the law and consequences	Previously found in sections on intimacy, sexual intercourse, community risks and hazards. In the new tool, inappropriate touch (age, relationship, consent, force) and consequences of this are now explored. This is virtually a missing topic in SSKAT and reflects a change in knowledge and attitudes towards sexual abuse and empowerment of rights.

Overview of Scoring and Interpretation

Some SSKAAT-R items require a response of "yes" or "no". Some require selection of a picture/drawing from three or four choices. Other items require a verbal description or explanation. Scoring information is found on both the Record Form and the Easel. A more complete description of scoring and interpretation is included in Chapters 4 and 5.

Attitude items are recorded for information only, and are not scored as "correct" or "incorrect". These questions are phrased so that it must be indicated if a particular behavior is "OK" or "NOT OK". Interpretation, therefore, is used only to understand the person's perspective.

User Qualifications, Cautions and Ethical Considerations

Qualifications

Generally, sexual educators, clinicians, and researchers who work with persons with developmental disabilities will be administering the SSKAAT-R. Administration requires less sophistication than interpretation of the findings. Qualifications will vary depending on the purpose:

- Assessment, as pre- and post-evaluation, will typically be conducted by a sexual educator
- Assessment, as part of a clinical evaluation regarding socio-sexual challenges, would generally be conducted by a qualified clinician (i.e., social worker, psychologist)
- Assessment for research may be done by trained research assistants, or students, if the data is for congregate, or collective interpretation, rather than clinical or individual analysis.

Ethical Considerations

Prior to administration, ethical considerations regarding consent and confidentiality should be determined.

Purpose of the assessment: The examinee must be informed about the purpose for conducting the assessment (i.e., research, to aid in developing a person-centered education plan, to assist in program evaluation, or for clinical or legal purposes). Consent to participate must be informed. The individual must also be informed of the ability to choose to not respond to a specific question, or to discontinue the evaluation at any time. Confidentiality of the data, and what will be done with the information, must also be disclosed.

Confidentiality: The individual must be informed regarding who will have access to the information garnered through the assessment, and provide consent for that disclosure to occur. In research, information on an individual must remain confidential and only anonymous, or congregate, data can be reported. However, if the individual is being assessed for clinical, legal or educational reasons, the information will likely be shared with other professionals. The individual must know the scope of that disclosure.

Examples of possible issues:

- Will parents have access to assessment data? What if their child is an adult?
- If the assessment is part of a court evaluation, what type of information may be disclosed in the courtroom?

Results may not always be confidential. For example, the assessment is often administered with the intent of sharing the results with others. There may also be limits on confidentiality because of the nature of the information disclosed (i.e., abuse). The examiner needs to know the limits of confidentiality and explain this in advance.

Dealing with Unexpected Disclosures

The SSKAAT-R does not ask individuals about their own sexual experiences, and as such, is not designed to solicit them. However, disclosure of abuse sometimes occurs. When it occurs, this information needs to be appropriately addressed. The examinee must be informed of this during the consent process. If someone discusses abuse, or an event that is dangerous to them or others, appropriate steps need to be taken. The examiner should follow the internal, agency policies for reporting abuse, or the guidelines provided in law and/or the ethics of their professional discipline. In the case of a minor, disclosure of abuse may require direct reporting to the authorities. In no case do we wish to lead the person to bring up memories or think they should be disclosing personal stories. However, should this happen, it must be dealt with according to the law, and with respect to the agency's policy.

Concern for Emotional Welfare
Examinees should not be required to answer any questions that make them uncomfortable. They should be allowed to take breaks, if necessary, and can discontinue the evaluation, at any time, without penalty. At the end of each section, the examiner should ask how the examinee is doing. If there is no answer, the examinee should be asked if a break is desired. If there are signs of discomfort, a break can be taken at any time. Discomfort signals might include changes in facial expression, body positioning or a change in responses, such as withdrawal or pressured speech. Discomfort can be recorded on the Record Form, with details on how it was managed (i.e., took a break, came back the next day to finish, brought a favorite staff member into the room, or chose to discontinue).

If the individual becomes upset by the assessment, that person should be asked if there is a desire to talk about it now, or at a later time.

Although a person may not show discomfort during the session there could be the rare occasion where the testing sparks a memory that may create a challenge following the session. It is often advisable to ask the staff, or family, who interact with the individual on a daily basis, to note whether the person begins to experience any residual upset as a result of the assessment. If this is the case, appropriate clinical support can be made available.

Caution in Using the SSKAAT-R as a Diagnostic Measure
As previously stated, the SSKAAT-R is an assessment tool, not a test. It may be useful as part of a clinical evaluation, including interviews, cognitive assessment, clinical history, impulse control, etc. However, it should not be used alone to evaluate consent capacity or predict sexual behavior. The SSKAAT-R may demonstrate that an individual has certain knowledge or attitudes, but it cannot predict how that knowledge will be used in a particular situation.

Let us take, for example, the practice item used to assess whether a person knows about condoms. It assesses the whether the individual knows:
- The purpose of a condom
- The steps to using a condom
- The skills to put a condom on an anatomical model (if the practice item has been assessed)

However, the SSKAAT-R cannot assess whether the person will use that knowledge when a condom is required. This is an area of generalization beyond its scope.

Overview of the Manual

There are seven chapters in this Manual. In the six remaining chapters, information on administration, scoring, development and interpretation will be presented.
- **Chapter 2** provides considerations for the use of the SSKAAT-R, including general administration guidelines.
- **Chapter 3** includes detailed administration instructions and methods of adapting the SSKAAT-R to meet individual needs.
- **Chapter 4** shows the Record Form, gives instructions, and provides examples of how to score the SSKAAT-R.
- **Chapter 5** provides information on interpretation of the SSKAAT-R, and offers case studies to illustrate its use, as presented in a clinical report.
- **Chapter 6** provides background data on development of the SSKAAT-R.
- **Chapter 7** describes the methodology and the field-testing results of the SSKAAT-R, including the research.