

# THE PSYCHOSEXUAL ASSESSMENT & TREATMENT CONTINUUM: A TOOL FOR CONCEPTUALIZING THE RANGE OF SEXUALITY-RELATED ISSUES AND SUPPORT NEEDS OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

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The sexuality-related issues and service needs of people with developmental disabilities (DD) have received increasing attention over the past two decades. This article introduces the Psychosexual Assessment and Treatment (PSAT) Continuum as a comprehensive schema for conceptualizing the broad range of sexuality-related issues and needs of this population. Each of the Continuum's five categorical domains (psycho-education, interpersonal, trauma, psychosexual disorder, forensic) are described and a discussion of its utility for practice is included.

*Keywords:* developmental disability, forensic, intellectual disability, mental retardation, offender, paraphilia, psychiatric disorder, sexuality

Recent years have given rise to a growing body of literature that has examined various aspects of sexuality and developmental disabilities (DD). Sexuality education,<sup>5, 29, 32, 49, 53, 57, 82</sup> sexual abuse,<sup>28, 36, 42, 44, 46, 51, 52, 59, 60, 61, 70</sup> HIV/AIDS,<sup>2, 22, 67</sup> paraphilia<sup>41</sup> and sexual offense behavior<sup>30, 34, 40, 56, 64, 72</sup> have all been explored as discrete entities. A variety of curricula,<sup>14, 15, 35, 39, 48, 58, 70, 74, 75, 80</sup> assessment<sup>23, 31, 34, 69</sup> and treatment<sup>8, 40, 54, 56, 59, 64, 76</sup> protocols as well as skill training programs<sup>67, 79</sup> have been published. All of these important works have contributed to an increased understanding of sexuality-related issues and service needs for people with DD. What seems to be absent from the literature is a broad-based framework for conceptualizing the range of sexuality-related issues/needs of this population, and its relationship to service provision.

The purpose of this article is to introduce the Psychosexual Assessment & Treatment (PSAT) Continuum as a means by which to conceptualize the broad range of sexuality-related issues and needs of people with DD. In addition, the PSAT Continuum is also offered as a practical tool for case assessment, treatment planning and delivery, as well as program planning. The reader is alerted to the fact that this article is intended to provide an overview of the model. As such, the discussions of each of the Continuum domains

are necessarily truncated. A series of follow-up articles providing more in-depth coverage of the discrete domains is currently in process.

## DEFINING SEXUALITY

As a conceptual model, the PSAT Continuum has adopted a very broad-based definition of sexuality. The literature in this area has been most helpful in establishing touchstones from which the entire PSAT Continuum has evolved. The following two definitions have guided this evolution:

All human beings have a need to care and be cared for. Ongoing communication with others is essential to our physical and psychological health. Sexuality is the way we define ourselves as men and as women. The definition is an important part of our self-esteem and can influence our interactions with others. The quality of our interpersonal relationships is, to a large extent, determined by how good we feel about ourselves as people worthy of receiving and capable of giving affection. Sexual activity is our most intimate way of giving and receiving affection.<sup>55</sup>

Sexuality [however] encompasses a great deal more than the physical aspects of sexual expression...sexuality can be

defined as the integration of the physical, emotional, intellectual, and social aspects of an individual's personality which expresses maleness or femaleness. People do not express their maleness or femaleness only in the bedroom. Sexuality is a part of all the activities in which a person engages. Work, socialization, decoration of one's home, expressing affection. Sexuality, then, is an expression of one's personality and is evident in everyday actions.<sup>16</sup>

### **THE PSAT CONTINUUM**

The PSAT Continuum is illustrated in Table 1. It consists of five categorical "domains" positioned on a continuous line that is read from left to right. The Continuum is designed to illustrate the progressive nature of specialization, and intervention modes that segue from teaching, to training, to treatment. It also emphasizes the need for increased levels of practitioner knowledge, self-awareness, and skill sophistication as one moves from left to right. The five domains include:

1. Psycho-education
2. Interpersonal
3. Trauma
4. Psychosexual Disorder
5. Forensic

Each domain is divided into two subcategories: "clinical issues" appearing above the bold arrow, and types of service appearing below the bold arrow. Types of service are further delineated into assessment and intervention modalities with the integral role of service coordination highlighted as well.

Consistent with the definitions of sexuality noted above, the PSAT Continuum is premised on four philosophical tenets:

1. Sexuality is an inherent, yet complex aspect of the human experience for ALL people.
2. ALL people require lifelong access to accurate information about sexuality in order to promote health and well-being.
3. People with DD are at comparable risk for the negative consequences associated with a lack of sexuality-related information and treatment services.
4. The quality of life for people with DD is enhanced by the availability of sexuality-related services throughout the life-course.

### **CONTINUUM DEVELOPMENT**

The PSAT Continuum evolved out of the committed efforts of an interdisciplinary group of clinicians employed by an outpatient DD clinic located in the metropolitan New York area. The clinic had the unique distinction of having committed itself to the provision of sexuality-related services by establishing a discrete PSAT unit. Weekly meetings extended over an 18-month period, provided the forum for exploring the nature of sexuality-related issues and needs encountered in the client population served by the clinic. This collaborative exploration gradually gave shape to the PSAT conceptual model. Represented in the group were five social workers (4 MSW's, and a Ph.D. clinical social worker), 3 psychologists (one master's level and two Ph.D. psychologists), a master's level rehabilitation counselor/Board Certified Sex Counselor, a master's level speech pathologist, and a Ph.D. art therapist. As such, the model reflects an eclectic, yet integrated theoretical orientation that was influenced by an ecological approach, growth and strengths-based perspectives, object relations, attachment, family systems, cognitive-behavioral, and ego psychological theories, as well as the principles of addiction medicine and applied behavior analysis.

### **Agency Policy**

Agencies provide the context within which the range of sexuality-related supports and services are rendered. Therefore, it is vitally important that every organization serving people with DD have written philosophies related to their clients'/consumers' sexuality and policies that provide guidance for addressing this aspect of their lives. Ideally, "sexuality-positive" philosophies and policies provide the cornerstone for all that an agency does in relation to this issue. The adoption of "person-centered" planning as a central feature in the field of DD offers a natural forum within which agency philosophy and policies regarding sexuality can be situated. As Lumley and Scotti<sup>43</sup> have noted, "By adopting a person-centered approach consisting of individualized assessment and program development, in conjunction with providing ongoing education, training, and support to staff (Scotti, Ujcich, et al., 1996; Weigle, 1997), agencies are taking an important, proactive role in supporting the sexuality of the persons they serve." (p.117)

**TABLE 1. THE PSYCHOSEXUAL ASSESSMENT AND TREATMENT CONTINUUM**

<b>CLINICAL ISSUES</b>				
<b>PSYCHO-EDUCATION</b>	<b>INTERPERSONAL</b>	<b>TRAUMA</b>	<b>PSYCHOSEXUAL DISORDER</b>	<b>FORENSIC</b>
<i>Sexuality Education and Training</i>	<i>Specific Skill Training in Interpersonal Relations</i>	<i>Trauma Counseling and Therapy</i>	<i>Assessment and Treatment</i>	<i>Sexual Aggression, Boundary Violation Assessment and Treatment</i>
Self-Identification (gender)	Basic social/ friendship skills	Acute victim issues	Trauma issues	Counterfeit deviance issues
Anatomy/ Physiology Facts	Basic dating skills	Chronic trauma issues (PTSD)	Interpersonal relating issues	Offender risk issues
Self-esteem/ Self-image	Intimate relations skills	Delayed trauma response	Sexual anxiety	First offense behaviors
Relationship awareness	Issue specific therapy		Sexual response issues	Repeat offense behaviors
Abuse awareness and prevention	Committed relationship issues		Paraphilia	
STD awareness and prevention	Self-identification (orientation/identity)			



<b>PROGRESSIVE SPECIALIZATION OF SERVICE</b>				
<b>PSYCHOEDUCATION (TEACHING)</b>	<b>INTERPERSONAL (TRAINING)</b>	<b>TRAUMA (TREATMENT)</b>	<b>PSYCHOSEXUAL DISORDER (TREATMENT)</b>	<b>FORENSIC (TREATMENT)</b>
<i>Socio-Sexual Knowledge and Attitudes Assessment-Revised</i>	<i>Circles curriculum</i>	Trauma assessment  <i>Trauma Symptom Inventory</i>	<i>Ecological Assessment Inventory</i>  Sexual compulsivity assessment	<i>Ecological Assessment Inventory</i>  Boundary disorder assessment
Sexuality Education	<i>Transactional Analysis groups</i>	Traumagenic Impact Rating	Masturbation assessment	Sexual compulsivity assessment
Abuse Prevention	Men's group, Women's group	Trauma and DD Tx Flowchart	Medication assessment	Individual therapy
STD Prevention	Couples counseling	Individual therapy	Trauma Assessment	<i>Project RESPECT group</i>
Individual Psycho-ed	Skills for intimacy group	<i>Project PRIDE group</i>	Individual therapy	Service Coordination
Consent for Sexual Contact	Sexual identity/ lifestyles group	Service Coordination	Group therapy	
Assessment	<i>Exceptional Parents training program</i>		Service Coordination	
Service Coordination	Service Coordination			

Match-Maroney, Boyle, Crocker, 2004

## THE CONTINUUM DOMAINS

**PSYCHO-EDUCATION**

The Psycho-education Domain of the PSAT Continuum subscribes to the SIECUS (Sex Information & Education Counsel of the United States) definition of sexuality education. “Sexuality education is more than anatomy and physiology. It includes an understanding of sexuality in its broadest context—sexual development, reproductive health, interpersonal relationships, affection and intimacy, body image and gender roles. ‘Sexuality education’—rather than ‘sex education’—conveys the holistic nature of the instruction.”<sup>32</sup>

In the PSAT model, sexuality education serves as the foundation upon which all other services are derived. Without accurate, timely knowledge, people with DD increase their risk for abuse or exploitation, unintended pregnancy, and HIV infection as well as involvement with the criminal justice system.

*Assessment*

Assessment within this domain explores general sexuality-related knowledge, values and attitudes. A thorough and comprehensive evaluation in these areas provides the baseline for planning a program of sexuality education. The authors have worked primarily with the Socio-Sexual Knowledge & Attitudes Assessment Tool-Revised (SSKAAT-R)<sup>31</sup> [and its predecessor, the Socio-Sexual Knowledge & Attitudes Test (SSKAT)<sup>84</sup>] as an evaluation tool for this purpose. Other tools such as the Sexual Knowledge, Experience, and Needs Scale for People with Intellectual Disability (SexKen-ID)<sup>50</sup> can also be useful in this task.

Consistent with SIECUS recommendations,<sup>32</sup> a PSAT knowledge, values and attitudes assessment explores the following topical areas:

1. Self-esteem and self-image
2. Anatomy and physiology
3. Menstruation
4. Masturbation
5. Relationships (dating, marriage, committed partners)
6. Intercourse and reproduction
7. Pregnancy, childbirth
8. Parenting
9. Sexual orientation
10. Contraception
11. Options for unplanned pregnancy
12. Sexual abuse
13. HIV/AIDS and other STD's
14. Sexual response
15. Personal responsibility

In addition to providing the baseline for planning, this foundational assessment also serves as a screen for some of the more complex and multifaceted issues located further to the right on the Continuum.

*Consent to Sexual Contact*

Although several elements of a formal assessment for Consent to Sexual Contact (“Sexual Consent”) are integral to an assessment used for the planning of a sexuality education program, there are some very crucial distinctions. A “Sexual Consent” Assessment has direct implications for an individual’s degree of autonomy in regard to sexual behavior. Moreover, unlike general sexuality assessments, “Sexual Consent” Assessments are often utilized by the courts in rendering legal decisions.

The issue of consent to sexual contact is one with which most agencies continue to grapple. In the absence of regulatory guidelines and standardized formats, agencies are left to create their own protocols for this important task. Perhaps the most salient feature of any “Sexual Consent” Assessment is that it be multi-modal, multi-dimensional and multi-contextual. In other words, it involves the collection of data from a variety of sources (including the individual him/herself), and a range of perspectives which represent the host of different settings within which the individual is situated. Moreover, a quality “Sexual Consent” Assessment assumes a “doors open” vs. “doors closed” approach. Rather than rendering a definitive determination in one direction or another, the assessment is viewed as dynamic and ongoing. The assessment is ideally used to identify specific areas of education, training or treatment needs that if addressed, may alter the individual’s capacity to consent. Structured sexuality assessments such as the SSKAAT-R and/or SexKen-ID may be utilized in this process, but only serve as singular contributing factors in determining a person’s capacity to consent to sexual contact.

Within any discussion of consent issues, it is critically important to acknowledge that the level/extent of some disabilities will preclude some people from the ability to consent to sexual contact. This is not to suggest that these individuals are not sexual people, but rather, that

fewer doors can remain open to them in terms of meeting their needs for sexual expression.

Needless to say, conducting consent assessments requires sensitivity, skill and tact on the part of each member of the assessment team, but particularly for the practitioner administering the formal evaluations. The skills associated with this task are gained through the experience of conducting several evaluations within the broader context of a supportive organizational milieu. Such a milieu is shaped by written philosophies and policies related to sexuality **and** a set of associated practices that afford the professional opportunities for training, networking and (optimally) mentorship geared toward honing their assessment skills and expertise.

#### *Intervention - Sexuality Education*

With a comprehensive assessment as the cornerstone for planning, a sexuality education program can be tailored to the unique needs of an individual or group of individuals. As noted earlier, there is no shortage of available sexuality education curricula. While some general sexuality education curricula can easily be adapted for use with people with DD, there are a good number that have been developed explicitly for use with this population.<sup>35,48,58,70,74,75</sup> The most important features to consider in evaluating any curriculum for use in sexuality education are:

1. Does it contain accurate and up-to-date information (especially as relates to rapid knowledge gains in HIV/AIDS, and scientific advances in contraception)?
2. Is it free of value judgements?
3. Is it well organized and easy to use?

A curriculum, however, should only be viewed as providing the framework for a program of sexuality education. As in any instructional situation, the teacher is the crucial element in the success of its delivery. Sexuality educators must possess an abundance of knowledge about human sexuality; they must be very aware of their own personal philosophy and perspectives on sexuality and be able to support and guide their students to clarify and develop these for themselves. A healthy sense of humor and genuine empathy for others are important personal characteristics for the sexuality educator. Employing a variety of teaching strategies such as art projects, role-plays, games, puzzles and other activities that create an atmosphere of interest and enthusiasm

are critical to sexuality education, and are especially important for those individuals with disabilities that may preclude the use of print resources.

Sexuality education for individuals with DD quintessential to their overall development and ability to manage, enjoy and celebrate this aspect of the human experience. This education can increase an individual's ability to be successful socially and vocationally. An individual's ability to avoid an unintended pregnancy or a sexually transmitted infection often correlates to the sexuality education and skill building opportunities they have been afforded. Agencies can proactively help ensure an individual's ability to give consent to sexual contact by providing comprehensive sexuality education.

#### **INTERPERSONAL**

The Interpersonal domain marks a shift from "teaching" (i.e., as in sexuality education) to "training," with a focus on skill-building and enhancement. General socialization training has long been a feature of DD services. However, facilitating skill development necessary for initiating and sustaining friendships, dating, and committed relationships has not.<sup>38,66,73</sup> Issues around sexual orientation and gender identity have been even less frequently addressed.<sup>3</sup> Although there are parents with DD who are trying their best to raise children, formal supports have not consistently been established to prepare them for this monumental task.<sup>24</sup> All of these issues fall within the purview of the Interpersonal domain on the PSAT Continuum.

#### *Assessment*

Information gained from the initial referral and subsequent intake interview, coupled with the outcome of the comprehensive sexuality assessment (discussed in the previous section) is utilized to identify priority or unmet needs in the Interpersonal skill-training area. While all individuals with DD benefit from general social skills training, the Interpersonal domain of the PSAT Continuum seeks to identify more specialized skill-training needs not typically addressed by general social skills programs.

#### *Intervention*

By its relational nature, the interventions of the Interpersonal domain are often logically delivered in a group modality, but also include couples or committed relationship counseling.

Options include socialization groups that might be organized around the Circles curriculum<sup>15</sup> or the principles of Transactional Analysis.<sup>7</sup> Men's and Women's groups provide the opportunity to build skills centered around the theme of gender identity. A "skills for intimacy" group affords participants considering an intimate relationship, with rich opportunities to build and practice associated skills. Curricula such as the Dating Skills Program<sup>79</sup> can provide a structure for organizing such groups.

Couples groups allow several established couples to provide mutual aid as they negotiate the vicissitudes of committed relationships. These groups offer opportunities for individuals to work on communication, compromise, problem-solving and anger management skills specifically as they relate to the experience of being part of a couple. Moreover, couples with DD often face the challenge of attitudes and/or perceptions of families and/or agencies who may minimize the significance of the relationship. The need for acceptance (if not validation) of the depth of their feelings, and strength of their commitment to one another, as well as recognition that their hopes and dreams are similar to those of people without disabilities, can all become a focus in couples groups.

Sexual identity and lifestyles groups offer critical social support and mutual aid to individuals with DD in the process of "coming out" and/or negotiating the myriad of biases faced by people of gay, lesbian, bisexual or transgender (GLBT) orientation in this society. Finally, an ongoing training and support program for parents with DD can enhance the knowledge, skill and coping abilities necessary for effective child-rearing.<sup>78</sup>

More specialized interpersonal skill training for individuals with DD requires that the practitioner, like the sexuality educator, possess an abundance of knowledge about human sexuality, an awareness of their own personal philosophy and perspectives on sexuality, a healthy sense of humor and genuine empathy for others. In addition, the practitioner conducting skill training within a group modality must also possess a sound understanding of group dynamics, a range of group facilitation skills and a firm belief in the value this approach offers to individual group members.

## TRAUMA

The Trauma domain on the PSAT Continuum centers on the experience(s) of trauma and its association to an individual's sexual development, comfort, and relationship success. Just as the Interpersonal domain marked a shift from "teaching" to "training," entre into the Trauma domain marks the next shift...the movement from "training" to "treatment." In so doing, it assumes a decidedly greater emphasis on the interrelationships of sexuality, trauma and mental health. Trauma assessment and abuse-focused treatment constitute the core of this domain on the Continuum.

For the purposes of this article, discussion of the Trauma domain will focus primarily on the issues of sexual abuse, assault and exploitation in the population of people with DD. However, it should be noted that the PSAT Continuum model recognizes the significant contribution of other types of trauma such as neglect, abandonment or maltreatment to the development of sexuality-related concerns. These will be touched upon in subsequent sections.

General population statistics suggest that one in five girls and one in ten boys are sexually abused in childhood.<sup>26</sup> Due to inconsistencies in definitions, reporting and data collection methods, exact prevalence rates are not known for those with DD. However, statistical estimates suggest a considerably higher prevalence in this population. McCarthy<sup>52</sup> reported a 62% prevalence rate in a sample of 185 people referred for sex education, while Sobsey and Varnhagen<sup>72</sup> suggest a 50% increased risk for the individual with DD. Similarly, Wilson and Brewer<sup>83</sup> have indicated that women with a developmental disability may be at 10.7 times greater risk for sexual assault than women without disabilities.

The mental health implications of sexual abuse have been well established in the literature. Initial effects include fear, anxiety, depression, hostility and inappropriate sexual behavior.<sup>13</sup> Long-term impacts include increased levels of depression,<sup>6,11,33,68</sup> anxiety,<sup>6,17,68</sup> poor self-esteem,<sup>6,17,68</sup> higher levels of somatization,<sup>11</sup> and sexual maladjustment.<sup>12,17,27,33,77</sup> More recent studies<sup>46,51</sup> are providing empirical support for the fact that people with DD experience the same range of effects as those without disabilities.

### Assessment

Within the PSAT model, several assessment instruments have been developed to assist in treatment planning. An adapted version<sup>47</sup> of the Traumagenic Impact of Maltreatment Rating Summary<sup>25</sup> and the newly developed, Trauma and Developmental Disabilities Treatment Flowchart<sup>19</sup> both provide a framework for multi-dimensional conceptualization about the impact of trauma and individualized approaches to the treatment process. Published assessment instruments such as the Trauma Symptom Inventory<sup>9</sup> may also offer direction in this regard.

### Intervention

Abuse-focused treatment for people with DD holds the same tenets as abuse-focused treatment for people without disabilities. Emphasis is placed upon understanding the significant contribution of the abuse experience to present-day difficulties, establishing a relatively egalitarian therapeutic relationship, and working from a growth and strengths orientation.<sup>10</sup> However, for the person with DD, a team approach including psychiatric assessment and psychopharmacological intervention (when warranted), collateral work with families and other service providers is tantamount to intervention effectiveness. Much of this collateral work is educative, and aimed at facilitating increased understanding of the dynamics of abuse and their specific manifestations in people with DD. Additionally, the training and coaching of significant others to support the individual is of crucial importance.

Treatment modalities typically include both individual and group as concurrent therapies. Treatment objectives are centered on strengthening and/or building ego functions (i.e., affect regulation, self-esteem modulation, and defining self-other boundaries), feelings identification, identifying abuse (in its varied forms), addressing cognitive distortions, the desensitization and processing of the traumatic event(s), abuse prevention training and personal safety planning. It is also likely to draw upon the foci of the Psycho-education and Interpersonal domains by either integrating sexuality education and social skill training into the therapeutic interventions or carefully coordinating the therapies with existent sexuality education and social skill training programs.

Original to the PSAT model, *Project PRIDE* is a time-limited group adapted from the work of Milner and Borgen-Jensen<sup>54</sup> and offered to women

with a history of sexual abuse. *Project PRIDE* was purposely designed with an empowerment approach as its foundation. The peer support and mutual aid of the group serve to decrease feelings of isolation, guilt, and shame, while bolstering assertiveness and personal safety skills. All of these help to mitigate the feelings of disempowerment engendered by the experience of sexual abuse/assault.

The clinician engaged in abuse-focused treatment must be a qualified provider of mental health services. He/she must have a solid understanding of dual diagnosis (mental health/DD) and strategies for adapting traditional therapy approaches to accommodate the needs of individuals with DD. Of particular concern at the right end of the PSAT Continuum is the therapist's knowledge of and ability to avert the phenomenon of diagnostic overshadowing. This concept speaks to the tendency to downplay or ignore mental health issues and to attribute emotional and behavioral difficulties to the developmental disability rather than to the effects of trauma.<sup>62,63</sup> Diagnostic overshadowing thus leads to a misinterpretation of presenting symptoms and, consequently, a mismatch of interventive services to address the concern. In some instances where sexual abuse has occurred, the mismatch of interventions may actually exacerbate the symptoms.

The abuse-focused therapist must keep current with the abuse and trauma literature, and be familiar with the intervention strategies that have either been empirically validated or are considered best practices within the field. Moreover, effective abuse-focused treatment for people with DD requires the therapist to be emotionally healthy, committed to continual self-reflection and evaluation, and respectful of both self and others. He/she must be able to avoid minimization and denial, as well as personalizing behavior; possess good listening skills, and empathic understanding. Additionally, familiarity with the legal system and comprehensive knowledge of applicable mental hygiene/sexual abuse laws and regulations as well as the policies of the agency(ies) within which services are provided are all important characteristics for the abuse-focused therapist.<sup>18</sup> The significance of ongoing clinical supervision and a network of collegial support cannot be overemphasized in the provision of treatment services in the Trauma, Psychosexual Disorder and Forensic domains on the PSAT Continuum.

## PSYCHOSEXUAL DISORDER

The Psychosexual Disorder domain of the PSAT Continuum focuses on various manifestations of psychosexual disorders in people with DD. Sexual anxiety may manifest in phobic avoidance of, or disdain for, anything related to sexuality (e.g., aversion to sexuality education, strong reactions to public expressions of intimacy, etc.); a disavowal of one's sexuality; or, at the other end of the spectrum, indiscriminate sexual behavior that devalues the sense of self. Sexual compulsivity may appear in patterns of masturbation or again, in indiscriminate sexual activity. The inability to reach a state of sexual arousal, maintain an erection or achieve orgasm are legitimate concerns for people with DD, though they are far less often presented as treatment issues in this population. The etiology of these concerns may have a multitude of roots including earlier experiences of trauma, medication effects or a lack of knowledge and/or skill. Their complexities, both in presentation and etiology clearly warrant the same competent clinical assessment and intervention as is available to the non-disabled population.

Perhaps the most frequently discussed issue of the Psychosexual Disorder domain is that of sexual behavior that is seemingly deviant or paraphilic in nature. It is important to note the distinction between true paraphilias and the commonly encountered phenomenon of counterfeit deviance<sup>23,34</sup> in this population.

Paraphilias are persistent patterns of sexual arousal in response to atypical or bizarre stimuli, accompanied by significant distress and impairment in functioning.<sup>4</sup> They typically involve either inanimate objects, suffering and humiliation or sexual activity with non-consenting partners. Hingsburger *et al.*<sup>34</sup> further categorize paraphilias as benign (i.e., sexual arousal by unusual fetishes or images that are not dangerous or offensive to oneself or others), offensive (i.e., sexual arousal achieved under circumstances that are offensive or dangerous) or indicative of hypersexuality (i.e., mental rumination and/or compulsive sexual behavior that significantly interferes with an individual's daily functioning). Though a full discussion of paraphilias extends beyond the scope of this article, they include:

1. Exhibitionism (compulsive, repetitive exposure of one's genitals to an unsuspecting stranger);
2. Voyeurism (colloquial "peeping tom"; masturbatory watching of an unsuspecting other);
3. Fetishism (sexual response to a non-living object, clothing or body part);
4. Pedophilia (sexual stimulation and activity with pre-pubescent children);
5. Sexual masochism (involvement in real acts of being humiliated, bound, beaten or otherwise made to suffer which result in sexual excitement for the individual);
6. Sexual sadism (involvement in real acts in which the psychological or physical suffering of another is sexually exciting to the person); and
7. Frotteurism (the touching or rubbing of a non-consenting person).

Conversely, counterfeit deviance is defined as "...behavior which topographically is deviant, but which, upon investigation is a result of some other unidentified factors."<sup>34</sup> These "unidentified factors"<sup>23</sup> may include:

1. A lack of information about sexual expression
2. A history of sexual victimization
3. Poorly developed social skills
4. Lack of assertiveness
5. Limited opportunity for sanctioned "age mate" relationships
6. Medication side-effects

Irrespective of etiology, it is vitally important to regard all sexually inappropriate behavior seriously and to pursue proper differential diagnosis.

### Assessment

The reader will note several "assessment" entries in the Psychosexual Disorders domain. The multi-contextual orientation of the Ecological Assessment Inventory<sup>23</sup> provides a holistic framework for evaluating sexual anxiety, sexual compulsivity, masturbation, trauma and medication effects. It suggests the examination of ten different factors in order to determine the likely etiology of the inappropriate sexual behavior and thus, to assist in the process of differential diagnosis. These factors include:

1. Basic applied characteristics of the problem;
2. Clarifying contextual issues related to the problem;
3. Assessing the impact of masturbatory problems in mediating the behavior;

4. Assessment of factors which maintain the behavior;
5. Assessment of the contribution of developmental and maturational factors;
6. Assessment of the contribution of sociological and co-existing behavioral and emotional factors;
7. Assessment of the individual's self-control skills;
8. Assessment of the individual's functional social skills and relationships;
9. Assessment of administrative support for the individual's socio-sexual behavior; and
10. Identification of available resources.

Beyond the Ecological Assessment Inventory's ability to direct clinical intervention (micro-level) it also provides clarity about the need for mezzo and macro level interventions. For instance, at the mezzo level, environmental interventions may include residential placement, or increased staff supervision. At the macro level, an individual's assessment may indicate the need to examine an agency or system's policies in regard to sexuality.

Additionally, within the PSAT framework, two instruments developed for a non-disabled clinical population<sup>65</sup> have been adapted for use with this population. The Sexual History Questionnaire for People with Developmental Disabilities<sup>20</sup> and The Sexual Behavior Profile for Persons with Developmental Disabilities<sup>21</sup> are both employed in conjunction with the Ecological Assessment Inventory in order to gain a deepened understanding of the presenting psychosexual issue. The Sexual History Questionnaire is a set of questions that can be used in gathering a sexual history as part of the assessment process. The Sexual Behavior Profile offers the clinician some guidance in assessing the type of sexual behavior, its frequency, whether the individual engages in the behavior alone or with another, and the feelings associated with the behavior.

Diagnosing paraphilias requires especially sensitive and judicious handling. While an accurate diagnosis provides a foundation for appropriate treatment planning, paraphilia diagnoses can often be misinterpreted by families and/or agency staff and may be inappropriately used as a rationale for restricting an individual's civil liberties. Moreover, unless the diagnosing professional is highly skilled in the process of differential diagnosis, assigning a paraphilia diagnosis can create a multitude of problems

including liability issues if appropriate treatment for the diagnosed condition does not follow.

#### *Intervention*

Treatment approaches for psychosexual disorders are as varied as the disorders themselves. Individual supportive therapy is recommended for the majority of sexual anxiety disorders. A combination of psycho-education and supportive therapy may be warranted in situations where indiscriminate sexual activity is the central feature. It is particularly important that individuals with DD learn about the potential risks (STD infection, pregnancy, personal safety) associated with indiscriminate sexual behavior, and, absent its cessation, develop strategies for self-protection. Compulsive masturbation or that which is otherwise self-injurious, may represent a skill-deficit. As such, individual skill training (sometimes accompanied by the provision of sexual aids) becomes the treatment of choice.

In the instance of a true paraphilia, recognition is given to the fact that often, early traumatic experiences have impaired constancy and regulatory ego functions leading to its development.<sup>37</sup> Given its long life, and the need to build ego functions, long-term treatment (i.e., a minimum of 24 months) is required to adequately address the concern. Moreover, for the individual with DD, a multi-modal treatment approach that addresses the intra-psychic, interpersonal and environmental factors associated with the paraphilia is recommended. Individual therapy, psycho-education and group therapy are often used in conjunction with one another. Additionally, collateral (coaching) work with family members, residential staff, etc. is critical for creating and sustaining support outside of the treatment situation. Depending on the individual's living situation and the nature of the paraphilia, environmental adaptations (e.g., increased supervision, residential placement, etc.) may be necessary to support the treatment effort.

Functional behavior assessments that identify the behavior as one of counterfeit deviance and more likely the individual's adaptive solution for sexual expression, also highlight the targeted areas for intervention. Often, these interventions are multi-modal and the individual may require a range of Continuum services. For instance, a lack of knowledge may point to the need for psycho-education, skill-deficits will point to the need for skill-training, a history of abuse, the need for abuse-focused therapy, etc.

Treatment objectives in this domain are centered on decreasing the frequency, intensity and duration of the behavior as well as the cognitive distortions associated with the psychosexual disorder while at the same time increasing awareness of feeling states (both of self and others), as well as the signal functions of those feeling states. For those with a paraphilia, increasing awareness of the impact on others, the triggers that prompt engagement in the behavior, the cycle of the paraphilic behavior and the legal, health, interpersonal and community implications of their behavior are all important objectives to be addressed in the treatment.

As should be evident from the above discussion, clinicians engaged in the treatment of psychosexual disorders of persons with DD, must possess all of the personal qualities and professional skill as the sexuality educator, skill-trainer and trauma therapist. In addition to the knowledge base shared by these practitioners, the clinician rendering services in the Psychosexual Disorders domain must be very familiar with the literature on sexual compulsivity and paraphilia, the vast majority of which has not included reference to their manifestations in people with DD. Consequently, the therapist must be able to extrapolate from this generic knowledge base and develop appropriate adaptations to accommodate the needs of people with DD.

#### **FORENSIC**

The Forensic domain on the PSAT Continuum concerns itself with the community-based treatment of individuals with DD who exhibit boundary violating or lower level sexual offense behavior. Because of its emphasis on community-based treatment, it does not address the needs of those who exhibit sexually predatory behaviors that place others at significant risk. For this group more restrictive placement (e.g., inpatient, developmental center) and milieu treatment are often warranted.

Boundaries give people a sense of self. They include perceptions of how we are different from others physically, intellectually, emotionally and spiritually; they serve a self-protective function. Intact boundaries result in an awareness of separate feelings, thoughts and realities. They help people to relate to others without: (a) insisting that they believe what we believe, or (b) feeling that we should think as they do. **Intact boundaries allow for closeness to others without undue feelings of overwhelm.** They ensure that

interpersonal behavior is appropriate and non-offending.

Boundaries can become damaged in many ways. Physical boundaries are typically damaged through violence, incest and/or neglect. Emotional boundaries are damaged by role reversal in families, emotional incest, shaming, humiliation and enmeshment. When such damage occurs, it can lead to an individual's "shut-down" and ignoring of physical and perceptual information that would otherwise serve self-protective functions. Additionally, emotional numbing (the sense that emotions are dangerous) and/or alexithymia (the inability to identify and utilize feeling states) may surface in response to this damage. The impact of boundary damage creates an increased vulnerability for repetitive abuse as well as an increased risk that the individual him/herself may engage in violating the boundaries of others. Ascertaining the degree of these risks is the focus of assessment in the Forensic domain.

#### *Assessment*

Assessment within this domain is interested in more closely examining the nature of boundary violating behaviors. Hence, a Boundary Disorder Assessment is actually a package of assessments that include a SSKAAT-R, a Sexual History Questionnaire, a Sexual Behavior Profile, a Trauma Assessment, and an Ecological Assessment Inventory.

#### *Intervention*

Given that boundary violating behaviors are multiply determined, their treatment must be multi-faceted, simultaneously addressing the many contributing factors. Like psychosexual disorders, the treatment of boundary violating behaviors is seen as long-term. Concurrent individual and group therapy is considered the standard of best practice in this area. If these services are delivered by different practitioners, close coordination between the treatment providers is of critical importance to the success of the combined interventions. Both treatment approaches need to be active and provide in vivo instruction. Moreover, the same collateral (coaching) work with family members and/or residential staff noted in the previous section applies to the treatment approach for boundary violating behaviors.

Original to the PSAT model, *Project RESPECT* (Recovery Encounters in Sexuality & Personality

Experienced through Communication & Trust) is a long-term, group treatment protocol for addressing the boundary violating behaviors of individuals with DD. It is best implemented with a maximal group of eight and the co-facilitation of two trained therapists. Since vicarious traumatization is a high-risk liability in running these groups, support in the form of designated “debriefing” time and ongoing clinical supervision are important features for the effectiveness of the co-leaders’ facilitation and by extension, the group itself.

The *Project RESPECT* protocol employs psycho-educational, skills-training, and psychotherapeutic interventions to address the multiple factors contributing to the boundary violating behaviors. The curriculum is structured in four parts: feelings identification, boundary clarification, anger management and empathy development. Common themes/issues and areas for intervention within the group include:

- Boundaries
- Shame
- Alexithymia
- Trauma
- Social skills
- Self-care
- Self-governance
- Self-regulation
- Healthy sexuality

Treatment objectives of both individual and group therapy are centered on:

1. increasing awareness and understanding of the issues (themes) associated with boundary violating behaviors;
2. creating capacity to experience a range of feeling states; restructuring of the cognitive distortions that fuel boundary violating behaviors;
3. developing strategies for self-protection, boundary maintenance, self-care, anger management, stress reduction and relaxation.

It is important to acknowledge that not every professional who provides sexuality education, counseling or therapy would be expected to treat individuals struggling with socio-sexual boundaries. The exploitive nature of offense-type behavior has a heightened capacity to provoke a myriad of counter-transference reactions in the practitioner. As such, an especially astute sense

of self-awareness, one’s “blindspots” and biases are crucial to the competent delivery of forensic services. Once again, the significance of clinical supervision and the support of a network of colleagues are highlighted as necessary components for effective delivery of sexuality-related services.

## **SUMMARY**

The sexuality-related issues and service needs of people with DD have received increasing attention over the past two decades. A body of literature on sexuality and DD now been established and provides considerable guidance on a variety of sexuality-related issues. The introduction of the PSAT Continuum contributes to that body of literature by offering a comprehensive schema for conceptualizing the range of sexuality-related issues and service needs of people with DD.

Examining sexuality-related issues from the PSAT perspective provides direction to service providers for the structuring and staffing of sexuality-related services. It speaks to the requisite knowledge, values and skills of staff engaged in this work. As a model, it can therefore assist in the identification of specific areas for professional development (i.e., training and supervision) needed to build an agency’s capacity to respond to the range of sexuality-related issues presented by individuals with DD. Moreover, the PSAT model offers a framework for individual assessment and treatment planning. Utilizing the Continuum to locate the presenting issue and underlying concerns, clinicians are guided toward the selection of appropriate interventions.

While the PSAT Continuum model has the potential to provide guidance and direction to sexuality-related services, a more fundamental concern must first be addressed. Sexuality-related issues and service needs do not share the same status as residential, day program, and vocational service needs. If indeed the DD service system values the espoused principles of independence, productivity, inclusion, self-determination and community integration,<sup>1</sup> then, as a system, it can no longer engage in the practice of benign neglect when it comes to issues of sexuality. Elevating the priority status of sexuality-related issues and services within the DD system will be necessary in order to the meet the unique needs of people with DD in this area.

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