



Addressing the Intimacy Interests of People with Mental Health Conditions: Acknowledging Consumer Desires, Provider Discomforts, and System Denial

a monograph from the Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities

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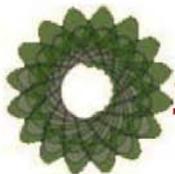
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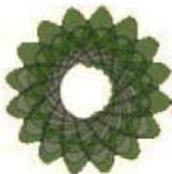


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The importance of sexual expression and intimacy

One does not have to inspect cultural norms too closely to conclude that it is a lifelong priority for both men and women to have a partner, spouse or significant other with whom to be sexually intimate. We see evidence of this drive for intimacy in the lives of everyone we know, and see it reflected as well on television, in popular movies, in the explosion of internet dating sites, and within most works of literature. The desire to enter into emotionally satisfying and sexually intimate relationships and to maintain such relationships underpins adult human experience. In fact, most people do sustain such relationships for much of their adult lives, and most routinely reflect on the quality of their relationships throughout the life cycle. Satisfying intimate relationships are considered highly relevant to overall health and mental health, for everyone.

With few exceptions and even under perfect conditions, the pursuit of sexually intimate relationships is fraught with mystery and no small degree of anxiety and complexity. In order to navigate the terrain of intimate relationships, often viewed as a crucial rite of passage, many of us rely on close family, friends, and even self-help articles and books to guide decision making. Our support networks are important and influential sources of advice, and often help to calm worries about possible rejection: Do you think she likes me? Is he someone who would make a good father? Is he attracted to me in the same way I am to him? Is she interested in being monogamous? Am I misreading her interest in me? What should I wear to a first date? When is it

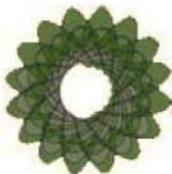


okay to become sexual? How do I talk to him about my fears without scaring him away?

While the thoughts, feelings, and actions related to the pursuit of sexual expression and intimacy are strongly guided by each person's unique cultural background, having and being a loving sexual partner is one of the 'adult social roles' integral to modern life. Making sense of this part of life can be both exhilarating and, literally, heartbreaking. This monograph looks at these complex and compelling issues from the particular and challenging perspective of people with mental health conditions.

Negotiating sexual expression and intimacy is different for persons with mental health conditions

As if this part of life was not challenging enough, individuals with mental health conditions face additional obstacles to exploring their sexuality and forging satisfying intimate relationships. However, it is important to note that even though the experience of intimacy is so important to human well-being and an issue of profound concern to people with mental health conditions, it is a topic largely ignored by most mental health providers. Whether in hospital or community mental health centers, whether in agency-run residences or consumer-operated drop-in programs, whether in assertive community treatment team meetings or peer specialist WRAP development sessions, there is often an absence of attention to this cornerstone of life. Individuals receiving mental health supports and services respond to this silence on the part of their providers by quickly learning not to expect support in this arena, and thus wind up grappling with their concerns about romantic and sexual relationships on their own.



Relatively little is known about ways that either traditional or peer support service providers can be successful in addressing consumers' desires for and concerns about sexual expression and intimacy. However, there is some literature revealing partnering patterns, consumer and provider perspectives, and emerging issues that offer a unique window into possibilities for a more forthright conversation about intimacy and a potential framework for effective interventions and more supportive environments.

Providers, administrators, policy makers and those with mental health conditions can, we hope, use this document to better understand the dimensions of this sensitive topic. We offer suggestions that mental health systems may use toward creating more positive climates that foster greater opportunity for sexual expression and spaces for the development of intimate relationships - a part of life that adults cherish and deem invaluable.

Challenges people with mental health conditions face in expressing sexuality and managing intimate relationships: desire

Patterns of Sexual Partnering: There is not a great deal of research that looks at sexual partnering patterns of people with mental health conditions. However, among those with the most serious and/or pervasive mental health conditions we do have evidence that consumers are much less sexually active than persons without mental health conditions. A study (Wright, Wright, Perry & Foote-Ardah, 2007) including a sample of 410 clients recruited across three community mental health centers and two state psychiatric hospitals shed important light on some of these patterns of partnering. Of this sample, 261 participants reported that they had been sexually inactive for the last three months. This subset of individuals then provided helpful



narratives that were analyzed and sorted into global explanations for their lack of sexual activity.

Reasons for Sexual Inactivity Mentioned by Consumers: Respondents to the survey identified eight thematic obstacles that potentially interfered with sexual activity:

- Poor access to sexual partners (39%);
- Experiences of sexual dysfunction (29%);
- Psychosocial challenges in forming relationships (23%);
- Fear of disease or pregnancy (23%);
- Moral concerns and/or hopes for a more meaningful relationship (23%);
- Sexually restrictive treatment cultures and residential settings (21%);
- Non-physical symptoms of with mental illness getting in the way (21%); and
- Feeling devalued, leading to withdrawal from others (14%).

Findings from the same study (Wright et al., 2007) revealed that those who had intimate relationships, often with different short-term partners, did not imagine the relationships leading to cohabitation or marriage. Other studies further underscore that only a small minority of persons with mental illnesses find and maintain longer term committed relationships (Buckley et al., 1999; Dickerson et al., 2004; Perry & Wright, 2006). Thus, even though interested in being sexually active and possessing the same needs for intimacy as persons without mental health conditions, consumers find they are much less sexually active than they would hope to be.

Medication Side Effects: Beyond having difficulty merely meeting someone interesting with whom to become sexually intimate, an important part of the story for many consumers is the frustrating sexual dysfunction that occurs from adhering to



prescribed psychotropic medication regimes. Many psychotropic medications effective in suppressing symptoms of mental illnesses can also significantly diminish natural interest in and capacity for sexual behavior. Thus, consumers become physically excluded from this treasured part of adult community life. Men and women report several similar concerns, but they also report different disappointments with sexual side effects of psychotropic medication.

Tennille and colleagues (2009) conducted a study that expanded on male and female thinking and behavior related to the impact of psychotropic medication on sexual performance.

Men reported:

- Frustration with the lack of physical desire;
- Difficulty getting and maintaining an erection;
- Worry about the fragility of their sexual response;
- A willingness to forgo condom use to better predict sexual performance; and
- The purchase of sexual stimulants 'on the streets' without physician supervision, to counteract side effects.

Women reported:

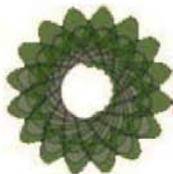
- Anger about lack of interest in sex;
- Difficulty with lubrication;
- Problems achieving orgasm; and
- Frustration with partners who also have mental illness and difficulty with sexual performance.



Providers and the context for consumer sexual expression: discomfort

While providers want to offer the best services possible to consumers with mental health conditions, when it comes to creating residential, treatment or community climates where sexual activity is normalized and where talking about sexuality and intimacy could take place, providers typically avoid the topic. Research indicates that providers still hold outdated views of consumers as asexual and generally feel uncomfortable broaching issues of intimacy. In advance of an agency based safer-sex intervention, a study by Solomon and colleagues (2007) found an attitudinal disconnect between consumers and their case managers. Consumers reported a strong interest in talking to case managers about sexual topics where, conversely, case managers displayed discomfort and did not believe that this should be a part of their role responsibilities. Furthermore, providers pointed to other priorities in services that should be attended to ahead of consumer sexual expression. Beneath this prioritization of work, providers have expressed worry that talk about sexuality, particularly if taking place in a consumer home, could somehow be misinterpreted (Encandela, et al., 2003) and conceivably violate boundaries in such private spaces.

Over the past two decades, providers have placed greater emphasis on preventing HIV and other sexually transmitted infections, but - perhaps out of discomfort with the topic - an exclusive focus on disease prevention has eclipsed the myriad contours of sexuality and intimacy. Thus, when the topic of sexuality is raised by providers with consumers, it is often couched in fearful terms and stern warnings to avoid unsafe sex.



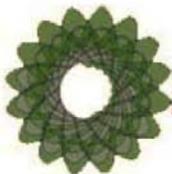
As previously mentioned, many providers operate from false assumptions about the people they serve, their sexuality, and the fundamental importance of intimacy to consumer well-being. Studies of provider beliefs in this area (Aruffo, Thompson, & McDaniel, 1996; Brunette, et al., 2000; Carmen & Brady, 1990; Grassi, 1996; Knox, 1989; McKinnon, Cournos, Herman, et al., 1999; Shernoff, 1988; Solomon, Tennille, Lipsett, Plumb, & Blank, 2007; Sullivan et al., 1999; Tennille, Solomon, & Blank, 2010) suggest the following persistent myths and fears:

Myths: providers hold false beliefs that:

- Consumers are asexual;
- Only 'young' consumers are interested in sexuality;
- Consumers who are sexual are heterosexual;
- Providers can quickly assess if a consumer is gay or lesbian;
- Only medical professionals are qualified to address this topic;
- Consumers inform their doctor about sexual side effects;
- Only consumers who are 'promiscuous' need information about safer sex;
- It is the providers' role to protect consumers from romantic rejection; and
- Dating and/or becoming sexually active will compromise the stability and progress consumers may have made.

Fears: providers also report being fearful that:

- Introducing the topic of sexuality and intimacy will be misinterpreted;
- Consumers might misinterpret a discussion about sexuality as a 'come on;'
- Consumers will ask the provider about their own sexual feelings/practices;
- Sexuality discussions will damage providers' working alliance with clients;



- Providers won't know how to talk about sex once the topic is open; and
- Consumers won't be able to handle the stress of dating or engaging in sexual activity, and experience symptoms or require inpatient treatment.

Providers are concerned about tripping over traditional boundaries and violating consumer privacy while possibly exposing themselves to questions about their own intimate lives. Moreover, providers worry about negatively impacting working alliances within established clinical relationships and are not sure it's their job to have these discussions.

Interestingly, another study by Tennille and colleagues (2010) revealed that working alliances were neutrally affected or even **strengthened** when case management personnel addressed issues of sexuality and intimacy with consumers. Consumers were pleasantly surprised to have been considered "more than just their mental illness." In this same study, a consumer was surprised that a newly trained case manager was asking about her sexuality. She responded, "Why are you interested? Usually, you just ask me if I took my meds." Case managers trained to discuss healthy sexuality with their consumers reported learning much more about consumers (not just related to sexuality and intimacy interests) when they were equipped with such additional clinical skills.

Working alliances neutrally affected or even **strengthened** when providers broach topic of sexuality with consumers



System policies that address issues of consumer sexuality: denial

However well-intentioned provider sentiments, consumers are deprived of a full right to sexual self-determination within treatment settings. Providers often enact rules and policies that treat consumer sexual behavior as additional symptoms of mental illness needing to be prevented or contained. Many residential providers continue to have rules that forbid sexual activity and do not allow for private spaces within residential settings. Thus, if a consumer were to spend a lifetime in receipt of such services, it would also be a lifetime devoid of sexual expression or the possibility for intimate relationships.

To be fair, providers, especially those running residential settings, have legitimate trepidation about wading into these uncharted waters. Faith-based provider services grapple with these concerns as they often care for consumers who do not share the same religious traditions or spiritual beliefs about expressions of sexuality. These organizations work to balance consumer rights to dignity and self-determination while holding moral hesitance about sex outside of traditional marriage. Other provider organizations do not believe that sexuality is an appropriate arena for public policy intervention. In between are a range of other provider types that recognize the importance of sexual expression and the need to assist consumers in addressing their needs within the consumers' own set of moral/ethical concerns, but are stymied by confusion over the role they can play.

Dr. Patricia Deegan, a pioneer of the recovery movement, laments that there are different standards for persons diagnosed with mental illnesses and for those who are not. A fundamental principle of the recovery movement is that there is '*dignity in risk and a right to failure.*' Keeping this one principle in mind can serve as a guiding light when we think of promoting and



supporting sexual expression and intimate relationships in our programs and service settings. Dr. Deegan would say that there is great irony that people without a diagnosis of mental illness have the “right” to make poor, un-insightful, self-defeating and even self-endangering choices about sexual partners – who to be involved with, when to marry, and when to have children (Deegan, 1999). Certainly there are no authorities rushing to the scene when those without mental illnesses make such decisions. Shouldn’t consumers be free to chart their own course, seek out the counsel they value, but ultimately make a few missteps regarding personal sexual expression and intimate relationships?

The cost of provider inability to address intimacy and sexuality with consumers

In the absence of policies on sexual interaction, particularly in longer term residential or inpatient settings, the likelihood is increased that staff will act arbitrarily to “sexual incidents” and respond to consensual sexual activity in ways that could violate a consumer’s liberty and dignity (Mossman, Perlin & Dorfman, 1997). Furthermore, consumers in community settings are often bereft of critical clinical guidance related to such issues as managing sexual side effects or securing private spaces for intimacy, and cope as best they can on their own. However, buying sexual stimulants ‘on the street’ without physician supervision or sneaking into a closet or alley for a few moments of sexual intimacy would appear avoidable indignities. There really are innumerable costs to lacking policy and avoiding dialogue on intimacy and sexuality concerns, among them:

- *Missed opportunities:* We miss a series of opportunities to work more productively with consumers concerning their hopes, dreams and desires with regard to having intimate relationships in their lives. There are great possibilities for

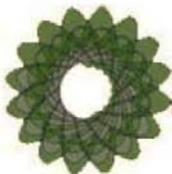


collaborating on strategies for safer sex should more candid discussions about intimacy and sexuality take place.

- *Reinforced stigma:* We reinforce stigma by ignoring or neglecting the “whole” person: consumers report that they appreciate being asked about their interest in dating and/or sexual relationships as this is a normal part of adult community life.
- *Poor care:* While great attention is given to erectile dysfunction in public media, consumer sexual dysfunction goes untreated, adding emphasis to the marginalization of persons with mental health conditions and causing stress. This type of alienation can increase mental distress and addictive behaviors in consumers (Lukoff et al., 1992), precisely behaviors the provider community would wish to ameliorate.

The behavioral health provider community has a great opportunity to facilitate much more dignified and communicative climates for consumers to talk about healthy adult sexuality. The benefits of doing so are many:

- Healthy sexual relationships can foster development and maintenance of new relationships, a key element in social integration; (Lukoff et al., 1992; Miller & Ingham, 1976; Vaughn & Leff, 1976)
- Positive sexual partnerships can increase quality of life, and those with mental health conditions who maintain relationships often have better treatment outcomes; (Ailey et al., 2003; Binder 1985; Dobal & Torkelson 2004; Shildrick, 2007; Welch & Clements 1996)
- Some research indicates that hospital readmission rates dropped if consumers were able to develop romantic relationships; (Shanks & Atkins, 1985) and



- Stigma of mental illness may be reduced. (Wright, Gronfein, & Owens, 2000)

What Can You Do?

There is a lot that can be done to improve how intimacy interests of people with mental health conditions are addressed within the mental health and healthcare systems, whether you are a consumer, a provider, or an administrator. The three tables provided here – organized around issues for systems, program providers, and consumers – offer a starting point for taking action to create more inclusive practices and policies and applies to you regardless of your viewpoint. You or your system of care may be at an advanced stage of removing obstacles to this important part of adult life or you may just be getting started. Remember that you do not have to alter your personal values or unique beliefs to be part of building a more recovery oriented system of care where consumers are engaging in self-determination and enjoying full and meaningful lives where intimacy and sexuality are afforded deserved attention.

Finally, developing collaborative workgroups with representation from a variety of stakeholders and identifying a structure for regularly scheduled working meetings is a fundamental prerequisite to your progress and great place to begin the change process. The tables below offer a helpful guide for discussion and planning.

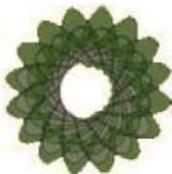
Depending on your stakeholder viewpoint (Systems, Provider, Consumer), we recommend a Needs Assessment, a Plan for Next Steps and a Plan for Implementation Evaluation to systematically reduce obstacles to consumer sexual expression and needs for intimacy.



Table 1: System Level (Policy makers or in-patient, residential, or outpatient administrators)

Needs Assessment

- Recovery oriented care affords individuals the opportunity to make choices related to sexual expression and intimacy by engaging in “responsible risk taking” without provider interference (Noordsy et al., 2000).
- What are the policies in existence in my system of care that promote this philosophy of recovery and community inclusion?
- What assumptions do policies, intake or assessment documentation in my system of care make about consumers’ interest in sexual expression and intimacy based on gender, age, speech, style of dress, mental illness diagnosis, race, or religious views?
- What assumptions do policies, intake or assessment documentation in my system of care make regarding whether consumers are heterosexual, asexual, or childless?
- How are consumers’ experiences with sexual side effects of medication handled by medical staff, other clinical staff, and peer providers?
- What policies exist/do not exist to support deliberate attention to healthy sexual expression and needs for intimacy for consumers?
- How do policies and the physical space of my system support access to dignified private spaces for consumers?
- What are physical signs in my system of care that demonstrate openness to sexuality: posters that show images of diversity – including children, two men or two women in an embrace; male and female condoms out and available for consumers.



Plan for Next Steps

- With the knowledge that policies forbidding consensual intimate relationships are inconsistent with the recovery model, strive to develop a system of care with updated policies that allow consumers to pursue sexual interests while affording safeguards from coercion (Van Sant, Ahmed & Buckley, 2012).
- Ensure that system policies assist consumers in clarifying their sex and intimacy needs while also distinguishing behaviors that pose safety or liability risks (Van Sant, Ahmed & Buckley, 2012).
- Develop a means within your system of care to regularly assess intake documentation and other newly introduced evaluative forms that may collect information on sexuality and intimacy interests for inclusiveness.
- Collaborate with providers, consumers and other relevant experts and stakeholders to prepare and train the entire provider workforce in your system to deliver sustainable evidence-based practices related to discussing sexuality and intimacy.
- Evidence-based practices like Shared Decision Making (SDM) or Motivational Interviewing (MI) can be helpful in promoting both consumer and provider comfort with difficult topics.
- Ensure that staff training is didactic and experiential with ongoing clinical supervision to prevent drift from newly developed skills.
- Support all provider types in additional training as needed to help consumers with social skills related to dating/relationships (Harper, 2011) in order to decrease anxiety and increase confidence.
- Support providers who are psycho-pharmacologists to deliberately address sexual side effects of medication with consumers.



- Make physical changes to your system of care to offer privacy to consumers to pursue sexual interests. Help consumers be responsible for the use of new private spaces.
- Offer consumers education about healthy sexuality to increase knowledge about sex, sexual health, pregnancy, sexually transmitted diseases, and the use of contraceptives.
- Exhibit physical signs that demonstrate openness to sexuality within systems of care.

Plan for Implementation Evaluation

- Determine a means of measuring provider competencies and fidelity to new clinical practices.
- Collect data on consumer satisfaction with new approaches taken by your system in addressing issues of sexuality and intimacy with consumers.

Table 2: Provider Level (Peer provider, psychiatrist, case manager, nurse, social worker, therapist)

Needs Assessment

- What are my personal biases and cultural views on sexual expression and intimacy?
- How did these views develop (family influences, cultural influences, religious and spiritual influences)?
- How do my personal views inform the way I talk with/don't talk with consumers about issues related to gender, sexual expression and intimacy?
- What are the myths and fears I have embraced in talking with/not talking with consumers I work with?
- What assumptions do I make about consumers' interest in sexual expression and intimacy based on their gender, age, speech, style of dress, mental illness diagnosis, race, or

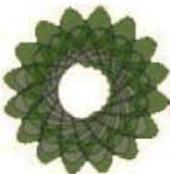


religious views?

- Do I assume that my consumers are heterosexual, asexual, or childless?
- What do I assume about my consumers' experience with sexual side effects of medication?
- What thought have I given to my consumers' access/lack of access to private spaces for sexual expression?
- What are the physical signs that demonstrate my openness to sexuality: posters that show images of diversity – including children, two men or two women in an embrace; male and female condoms out and available for consumers.

Plan for Next Steps

- If your program has not yet addressed this important topic, be the first to advocate beginning the discussion.
- Don't go it alone! Ask for help from supervisors and advocate for the inclusion of relevant stakeholders, particularly consumers, in the effort to revise documents, policies, and/or develop trainings to develop or improve upon clinical skill.
- Ensure that issues related to sexual orientation are addressed in treatment-planning for consumers who are also sexual minorities. Include such experiences as homophobia, heterosexism, and stigma in provider settings (Cook, 2000).
- Learn to work with clients on developing social skills related to the pursuit of intimate relationships and, for those consumers that are interested, rehearse scenarios related to dating such as starting and keeping a conversation going, asking someone out on a date, expressing positive feelings, and negotiating condom use.
- Ask for and participate in continuing education that enables you to feel confident to talk with clients about topics of sexuality and intimacy.



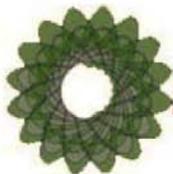
Plan for Implementation Evaluation

- Participate in refresher trainings to keep up with your new clinical skills.
- Be a 'watch dog' in your setting and make sure that practices and documentation remain inclusive of topics related to sexuality and intimacy interests of consumers.

Table 3: Consumer Level (Recipients of service)

Needs Assessment

- What are my personal biases and cultural views on sexual expression and intimacy?
- How did these views develop (family influences, cultural influences, religious and spiritual influences)?
- How do my personal views inform the way I talk with/don't talk with providers about issues related to gender, sexual expression and intimacy?
- What assumptions do I make about my providers' interest in my needs related to sexual expression and intimacy based on their gender, age, speech, style of dress, race, or perceived religious views?
- Can I speak with my providers if I am experiencing sexual side effects of medication?
- What are my goals for sexual expression and intimacy? Is this something important to me right now that I would like help and support with?
- What type of support would I want (if any) from my providers on these issues?



Plan for Next Steps

- If your program has not yet addressed this important topic, and this is important to you, be the first to advocate beginning the discussion.
- Talk to providers about any interest you have in getting involved in the effort to revise documents, policies, and/or develop trainings to develop/improve your services.
- Expect support on issues related to managing sexual side-effects of your medication.
- Understand that it is your right to talk about your concerns related to healthy sexuality and intimacy with providers.
- Be clear that you always have the right not to talk about these topics if you prefer to keep them private.

Plan for Implementation Evaluation

- Talk to your providers about your experience of changes made to your services related to supporting you in pursuing intimate relationships.

Conclusion

It is possible to collectively and strategically address barriers to consumer sexual expression, avoid practices that unnecessarily limit opportunities for intimacy, and open the door to this vital component of community inclusion. In order to accomplish this goal, we must be mindful of consistently creating spaces where consumers can realize hopes, dreams, and desires, a central component of a person-focused system of care. Finally, remembering that there is great dignity in risk and a right to failure in all domains of community life, policy makers, administrators and providers possess the potential for developing more thoughtful collaborations with consumers on this essential domain of human experience.



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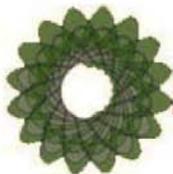
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Helpful Websites

National Gay and Lesbian Task Force
1325 Massachusetts Ave NW, Suite 600



Washington, DC 20005
Phone: (202) 393-5177
TTY: (202) 393-2284
www.thetaskforce.org

American Association of Marriage and Family Therapy
112 South Alfred Street
Alexandria, VA 22314-3061
Phone: (703) 838-9808
www.aamft.org

Toolkit Inclusive of Tips for Dating and Sexuality

The Social Enhancement Workbook

The Social Enhancement Workbook provides a step-by-step guide for consumers, case managers and other support personnel with regard to increasing the consumer's participation in a wide range of social activities (including dating and sexuality) in community settings: tested in a variety of community mental health and psychosocial programs, the 'workbook' is a useful guide to groups and individuals.

Individuals or organizations interested in training or technical assistance on this topic should contact Richard Baron at the Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities / rcbaron@temple.edu

