Soins et services

Guidelines on the Sexual Lives of Hospitalized Patients in the IUSMM'S Intellectual Disability Psychiatry Program

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Guidelines on the Sexual Lives of Hospitalized Patients in the IUSMM's Intellectual Disability Psychiatry Program

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Introduction

For several years, the clinicians and managers in the intellectual disability psychiatry program have been concerned about the affective and sexual lives of their clients. Preventive, instructional and therapeutic interventions related to sexuality are regularly performed in the program units. As we have seen, our clients, who already have significant needs in the various adaptive spheres, may also need help in the sexual sphere.

A large portion of the clients who have been residing at the Institut universitaire de santé mentale de Montréal (IUSMM) for several years is relatively stable in clinical terms. These clients are waiting to be integrated into intellectual disability rehabilitation centres (CRDIs) or long-term care centres (CHSLDs). They may have created significant bonds with other clients in the unit or in other program units or hospital units (internal or external). For these clients, the IUSMM was and still is "a home," until they integrate into a new living environment.

A second group of clients is those who are not stable enough to be directed to residential centres. Often, after being hospitalized for several years, these clients still have developed very few or no close bonds with people living or working at the IUSMM.

The different types of clients and contexts reveal significant disparities that clearly influence our position on sexual contact between clients, including the duration of hospitalization, intimacy bonds created with other clients, undergoing active psychiatric treatments versus awaiting housing (housing situation), their clinical condition and whether living as residents or not. It is important to consider these aspects while reflecting on the effects on those we are responsible for during their stay.

These guidelines aim to orient and outline interventions regarding the affective and sexual lives of clients with an intellectual disability (ID) or with ID and pervasive developmental disorders (PDD), for whom we provide clinical services. The guidelines consider the person's specific context, in light of a philosophy based on support and protection.

Our hope is that these guidelines will drive the daily thoughts and actions regarding the affective and sexual aspects of our clients' lives. As these aspects are intimate but nonetheless significant parts of human experience, they will be considered, discussed, analyzed and understood rather than avoided or ignored because our staff lack direction, guidelines, support and coaching.

Overview of the services and the clientele

This document also presents elements of a literature review on the affective and sexual lives of people with an ID or ID-PDD, to enhance our knowledge and understand the various aspects and issues of this aspect in our clients' life.

Finally, the implementation of the guidelines will be presented to ensure they are adopted by all the staff.

Guideline objectives

For clients and their relatives

- To recognize the right to express affective and sexual needs by considering the persons' characteristics and the services provided by our program.

- To recognize the right to have access to assessments and adapted interventions regarding sexual disorders, especially those that compromise residential and community integration.

- To make it possible to obtain the required services (assessment, information, training, support, coaching, treatment, therapy) for affective and sexual matters.

For care providers

- To outline the expected attitudes and behaviours of the care providers regarding the affective, love and sexual lives of our clients.

- To recognize the rights of our clients to have access to assessments and adapted interventions regarding sexual disorders, especially those that compromise residential and community integration.

For the program and the institution

- To describe and support the interventions regarding the expression of an affective and sexual life and regarding sexual issues and disorders.

Elements of the literature review related to the guidelines

The literature review on the sexuality of people with IDs or ID-PDDs was not intended to be exhaustive; the aim was to pinpoint certain aspects that seem significant in and pertinent to the guideline-implementation process.

Realities and issues on the sexuality of people with an intellectual disability

- People with an intellectual disability are often perceived as eternal asexual children. Overprotection may lead to "hypersexualization" in reaction to the restrictions and limits imposed by the environment. As a result, the person is at risk of reacting impulsively, without considering the environment's limits.

- The sexuality of people with an intellectual disability has been widely ignored.

- People with an intellectual disability have rarely received a thorough sexual education. The information received is usually focused solely on problematic sexual

behaviours. There is little empirical data regarding the nature and the frequency of adaptive sexual behaviours.

- The peers of people with an ID also tend to have little knowledge and experience regarding sexual matters.

- People with an intellectual disability have a limited access to appropriate and accessible educational resources.

- The relatives, care providers and helpers are often embarrassed about topics related to the sexual lives of people with an intellectual disability.

- Professionals may think they are entitled to manage the sexual behaviours of people with an intellectual disability, to the point that they do not consult the person concerned.

- Professionals tend to overprotect people with an intellectual disability, thus denying them the *dignity of risk*. Overprotection prevents any kind of sexual expression.

- The staff show a more open-minded attitude toward sexual behaviours of people without an intellectual disability compared to those with an intellectual disability.

- To protect vulnerable clients, it is necessary to consider their abilities, the maturity level and the developmental age, so they can make decisions regarding their social relations, sexual expression, contraception and decisions related to pregnancy. By using the word "protection," we hint at the importance of acting with caution and promoting socio-sexual education, support and an adapted assessment of the clients' needs.

The clients have the right

- to intimacy;
- to confidentiality;
- to freely express their sexual orientation; and
- to freely express their sexuality, while respecting others' choices

The ability to consent is a major issue. The following elements should be taken into consideration in light of this complexity:

- Protect those who cannot make certain decisions regarding sexual matters.

- Evaluate the ability to provide sexual consent as soon as it is required.

- Even if the person can consent, it does not mean that he/she will exhibit responsible sexual behaviours.

- Sexual education or additional guidance may be beneficial for the person, but they are not necessarily required to engage in sexual activity.

Vulnerability to sexual assaults

- Several studies indicate that up to 90% of those with an intellectual disability have been, at some time in their lives, assaulted or sexually abused. Also, sexual abuse was found to occur repeatedly.

- Several vulnerability factors may contribute to increasing the risk of a person with an intellectual disability to become a victim of sexual assault or display inappropriate behaviour to the general public. Below are some of these factors:
  - Their communication difficulties
  - The lack of credibility given to them
  - Their lack of knowledge and education concerning sexuality
  - Their difficulty recognizing a potential danger
  - Their difficulty discriminating between appropriate and inappropriate or criminal gestures
  - Their isolation
  - Their need for affection and attention
  - Their economic, physical and psychological dependency
  - Their lack in interpersonal skills
  - Their general experience of submission and obedience to rules
  - Their lack of decision-making authority and empowerment over their lives
  - Their lack of self-esteem
  - Their ignorance of their right to refuse to be involved in actions they do not wish to take part in

What are the consequences of sexual assault?

Physical consequences:

- Sexually transmitted infections
- Pregnancy
- Genital lesions

Psychological and behavioural consequences:

- Depression, depressive states
- Anxiety
- Regression to a lower developmental stage
- Difficulties with interpersonal relations, isolation from others
- Showing discomfort when touched
- Showing discomfort with a specific person;
- Lack of efficacy at school or work
- Sexual disorder
- Health problem
- Fear, anxiety, post-traumatic stress disorder
- Poor self-esteem

- Sleep disorders, insomnia
- Behavioural disorders, inappropriate sexual behaviours

How to prevent sexual assault against people with an intellectual disability?

Prevention for people with an intellectual disability

Using instructional programs and tools adapted to their understanding, it is possible to teach people how to prevent sexual assault (e.g. identifying situations likely to lead to sexual assault, and refuse this type of situation; teaching people how to defend themselves against individuals who may cause harm). Over the long term, an indirect result of implementing the guidelines and attending socio-sexual workshops should be a decrease in the number of sexual assaults.

- **Institutional prevention**

  According the *Association du Québec pour l'intégration sociale* (AQIS), institutional prevention should be included in services provided to people with an ID. Each institution should :
  - train staff members and volunteers according to the vulnerability of the clientele.
  - implement mechanisms to report and manage situations of aggression.
  - promote the short-term and long-term support of victims (e.g. intervention protocols for situations of aggression).
  - work with partners in all actions to prevent or manage situations of aggression.

- According to the *Fédération québécoise des centres de réadaptation en déficience intellectuelle et en troubles envahissants du développement* (FQRDITED), the main factors to ensure the success of a preventive approach are :
  - the constant supervision of staff members and volunteers working with the clients, and
  - the distribution of a guide to promote prevention awareness among care providers.

Interventions for victims of sexual assault

People with an intellectual disability may communicate that they've been the victim of a sexual assault to their circle by talking about it or by behaving in a more or less appropriate manner. Unfortunately, their entourage may not listen to them, believe them or be able to read the changes in their behaviour.

- Care providers must
  - stop the abuse,
  - provide support that is adapted to the victim's needs, and
  - make sure a follow-up will be planned and that all measures have been taken to prevent another assault.

General guidelines of the intellectual deficiency psychiatry program

The guidelines are mainly based on Haracopos's works (2009).

- Clients have the right to lead affective and sexual lives in accordance with their needs and desires and to manage their lives their own way as long as they do not hurt or harm others.

- Care providers should take a positive, individualized, respectful, empowering and safe approach in their interventions with clients on matters of sexuality.

- Clients have the right to receive support and guidance in learning and expressing affective and sexual dimensions.

- Clients have the right to receive support and guidance regarding their unresolved sexual issues.

    - The type of guidance must be related to the manifestation of the client's sexual issue in the environment. It is crucial to determine and assess whether the signs of problematic sexual behaviours are definite, uncertain or absent.

    - If the person exhibits definite signs of sexual behaviour that are compatible with an unresolved sexual issue, intervention is required.

    - If the person exhibits uncertain signs of sexual behaviour that are compatible with an unresolved sexual issue, additional observation and information should be collected to determine whether they are related to a sexual problem or not.

    - If the person with an intellectual disability does not exhibit any signs of sexual behaviour that are compatible with unresolved sexual issues, the environment should not deliberately stimulate sexual compulsions.

    - It is mandatory to prepare a plan for guidance to be approved.
        - A systematic analysis of the person's sexual behaviour should demonstrate that his/her needs are caused by an unresolved sexual issue.

        - A instruction and guidance plan should be developed to help the person address his/her sexual needs and, if possible, to teach the person to fulfill his/her needs by him/herself, while respecting social standards and rules.

        - Before the plan is applied, it should be discussed and approved by the interdisciplinary team, those involved and their families, to prevent unfounded criticism and judgement. The responsibility should be shared. Support may also be provided to significant members of the

client's entourage, if needed, to ensure consistency in the interventions and a generalization of the instruction.

- The plan must be developed with and approved by the client, so that the sexual instruction is done with his/her consent.

- If the person is not able to decide or approve the plan, the team will be responsible for making decisions, while taking his/her needs and situation into account.

❖ The program managers furnish the care providers the support and training to develop the skills and familiarity with the topic needed to intervene in sexuality matters.

The program's positions on various themes related to sexuality

Inspired by the Québec CRDI's overview (2004) and the Estrie CRDITED's policy (2011). The following themes are from the literature and are relevant in the context of our program.

❖ **Sexual contact between clients**

Sexual contact is "a touch or a caress of the person's sexual parts or other intimate parts, in order to satisfy a sexual desire, whether it is a direct touch or over the clothing" (Samowitz, 2009).

Generally, sexual relations between clients, whether they are of opposite or same sex, may be allowed to occur, provided that the following conditions are met:

- ❖ The two partners are able to provide informed consent and agree to have sexual contact together.
- ❖ Having sexual relations is not harmful for the person given his/her own clinical condition. This element is particularly significant for people undergoing evaluation.
- ❖ The sexual contact occurs in a place that safeguards intimacy and privacy.

We are not allowed to prohibit sexual contact between consenting clients who are able to understand what they are doing if their behaviour does not harm them and occurs in private.

Any form of power, domination or dependency should not be part of a freely expressed decision to have sexual contact. Support should be provided to help clients make informed choices, understand the reasons behind our position or find alternatives to unwanted behaviour. The least invasive and restrictive type of support should be provided.

❖ **Masturbation**

Masturbation is the self-stimulation of the genitals using hands, objects or body parts in order to obtain sexual pleasure. People masturbate for various reasons related to pleasure and leisure. Masturbation is a normal sexual behaviour that can occur at any age. Anyone—man or woman—may choose to practise masturbation.

An instructional intervention may consist of helping the client, the relatives and the care providers learn more about female and male masturbation, as well as the places, the safe behaviours and the hygiene rules regarding masturbation.

If needed, masturbation training may be performed with the person, within the context of a determined protocol in an approved plan that respects the general guidelines presented above.

Particular attention should be paid to adopting empowering, guilt-free and non-invasive instructional attitudes during the interventions.

❖ **Use of erotic material**

Concerning intimate relations, the objective is to promote interpersonal exchanges that respect the client's abilities and interests. Also, the ability to consent should be the first priority, based on the philosophy of client protection.

The use of pornographic material is banned. Pornography is an indulgent representation of subjects and obscene details in artistic, literary or cinematic works. The scenes emphasize a close-up view of the genitals, without representing bodies or interaction between individuals. A pornographic movie, or porno-flick, is a movie containing scenes where human sexual acts are explicitly and deliberately shown to excite the spectator.

Erotic material may be tolerated provided that the person uses it safely and respects privacy and socio-sexual standards. Eroticism or "loving desire" describes the phenomena that trigger sexual desire, and the various representations, especially cultural or artistic, that express and give rise to these sensations. Eroticism may also describe, by extension, the nature of relations between two individuals attracted to each other. The scenes and photos emphasize partially or completely naked bodies, without a direct representation of the genitals. The focus is on the interaction between the people and the sexual, erotic desire.

Erotic material includes objects and media used to stimulate or enhance sexual excitation and pleasure. This type of material may also represent acceptable alternatives for clients using objects that may harm their health or personal safety (e.g. use of hazardous objects for masturbation). In this type of situation, discuss with the client how to replace the object with a safer one with the same functions. This support would be provided in the context of an adapted sex-education approach with the person, allowing him/her to make more appropriate and less harmful choices when using this type of material.

Of course, it is crucial that the person be informed and instructed on the issues and rules of safety for using this type of material.

Depending on the clients' profiles and characteristics, it is important to pay particular attention to those who use this kind of material compulsively in order to help them develop a less reductive view of sexuality. The objective is also to avoid contributing to the development of dependency on this kind of material.

❖ **Use of fetishes**

A fetish is a body part or object used to obtain sexual satisfaction.

The use of fetishes, alone or with another person, is tolerated, provided that it is not harmful to the users, is safe, and does not become overwhelming or compulsive.

❖ **Contraception**

Contraception includes a range of biological, technical or natural methods that prevent procreation. It is a significant element for the sexual health and general well-being of the clients.

The instructional intervention in this field consists of

- ❖ providing information and helping the person to choose the most appropriate method of contraception, and
- ❖ providing the required help regarding the chosen method.

❖ **Prevention of sexually transmitted infections**

Sexually transmitted infections (STI) may influence the general health, well-being and reproductive capability of those affected. Several means may help the people prevent and control STIs and their adverse effects.

The instructional intervention consists of

- ❖ providing information about STIs to better understand and avoid them, and
- ❖ providing information and encouraging the use of those means to prevent or protect one's self against STIs:
  - ➢ Use condoms.
  - ➢ Adopt safe sexual behaviours.
  - ➢ The program's clients have access to condoms if needed.

❖ **Sexual assault involving another client: prevention and intervention**

Sexual assault is "an act that is sexual in nature, with or without physical contact, committed by an individual without the consent of the victim or in some cases through emotional manipulation or blackmail, especially when children are involved. It is an act that subjects another person to the perpetrator's desires through an abuse of power and/or

the use of force or coercion, accompanied by implicit or explicit threats" (Gouvernement du Québec, MSSS, 2010).

It is important to mention that psychiatric institutions have an obligation to protect residents or outpatient clients, which, given the circumstances, is an obligation of methods. Consequently, institutions must develop a policy on sexuality.

Prevention

For clients:

- To learn to recognize circumstances that are likely to lead to an assault as well as how to say "no" and how to refuse these types of situations.
- To learn appropriate sexual and social behaviours.
- To learn that it is possible to be in control of one's life and to learn how to protect one's self against individuals who may cause harm, etc.

For care providers:

- To recognize the possibility that forms of domination and dependence against the clients may exist and may be considered abuse.

Intervention for clients who are victims of a sexual assault

All staff should immediately report any situation that may cause a form of domination or dependence over clients. Support will be offered to employees who report such a situation. When a client is a victim of sexual assault, the following interventions should be performed:

- Implement measures to ensure the person's protection.
- Hold a clinical meeting.
- Direct the person to go to a hospital to begin the medico-legal procedure within the first few hours of the assault. (The "sexual assault evidence kit" protocol is available in institutions for all sexual assault situations.)
- Provide support adapted to the victim's needs.
- Provide support for the client's family.
- Ensure that the situation is followed up and that measures will be implemented to prevent another assault.

Interventions for the perpetrator when also a client

- Provide support adapted to the client's needs.
- Hold a clinical meeting.
- Implement measures to ensure the person's protection.
- Provide support for the client's family.

- ❖ Ensure that the situation is followed up and that measures will be implemented to prevent another assault.

❖ **Severe sexual behaviour disorders**

Sexual behaviour disorders are sexual practices that violate the physical or moral integrity of the individual or of another. These disorders include all sexual deviances, several of which are subject to prosecution or judicial sentencing.

Our program acknowledges that such behaviours may violate the client's physical or moral integrity. Therefore, a preventative and intervention-based attitude is preferred, in order to quickly identify the disorders and to implement an action plan in the care setting.

In the event that the program's medical and professional resources do not have sufficient specific expertise on inappropriate sexual behaviours and severe sexual behaviour disorders, highly specialized support is provided to the service users and the staff. (e.g. *Centre de psychiatrie légale de Montréal*, SQE-TGC).

The program's co-managers, supported by the co-directors of the Direction of Clinical Services, should establish the required partnerships to make this type of help available. If the planning and the interventions require the support of experts in the field, this procedure should be followed:

1. The manager, treating doctor or professional involved presents the detailed situation to the program's co-managers.

2. The co-managers take the formal steps to obtain the highly specialized support or instruct the program's managers, doctors or professionals to do so.

3. A follow-up is conducted with the program's co-managers and the program unit managers regarding the ability to secure the specialized support.

Conclusion

The aim of this document is to allow the clients to express their sexuality within specific parameters. By clearly outlining the interventions, the clients will be able to achieve a sense of well-being, given their conditions and needs.

We also hope to demystify taboos and prejudices surrounding the sexuality of those for whom we provide services on a daily basis. We want to better equip the staff to help them intervene in this adaptive sphere. The staff's improved knowledge, people skills and know-how will enable the clients to experience their sexuality safely, with pleasure and while respecting themselves or others.

Finally, we want to promote the best assessment, intervention and guidance practices on matters of sexuality and encourage new research projects based on assessing the guidelines' impact.

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L'Institut universitaire en santé mentale de Montréal offre des services spécialisés et surspécialisés en psychiatrie. Chef de file dans son domaine, l'établissement a mis en place un dispositif varié et innovateur de services de traitement, de réadaptation et de réhabilitation qui répond aux besoins multiples de sa clientèle.

À la fine pointe des connaissances, le Centre de recherche de l'Institut universitaire en santé mentale de Montréal est le plus important lieu de recherche en santé mentale dans le milieu francophone canadien. Il regroupe le plus important nombre de chercheurs en santé mentale des facultés de médecine, des arts et des sciences et des sciences infirmières de l'Université de Montréal et d'autres universités.

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