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ORIGINAL ARTICLE

Supporting the sexuality of the intellectually disabled: How institutional change and vocational training can help[☆]



J.-S. Ménoreau^{a,*}, A. Dupras^b

^a 21, rue du Chapeau-Rouge, 44000 Nantes, France

^b Département de sexologie, université du Québec à Montréal, case postale 8888, succursale centre-ville, Montréal H3C 3P8, Québec, Canada

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Summary This article explains how peoples' attitudes have changed in past years to sexuality for the disabled. This change in attitude has been largely fostered by the extensive work of reflection on the involvement of the administrative authorities and the acquisition of new competences by carers, helping them to integrate this new mindset to the multitude of individual situations that can arise. By adopting a medical-social model, we have been able to move away from a "care-based" system towards a "support-based" system for helping clients with their sexuality. Professionals need theoretical and institutional landmarks in order to best meet client needs. Managers of care facilities must play a leading role in developing an institutional project for sexuality that will be a guideline for carers in deciding what action to take in a given situation to support the sexuality of residents.

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Introduction

The way disability is considered has changed in countries with legal provisions to uphold the rights of the disabled.

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* Corresponding author.

E-mail address: jean-simeon.menoreau@wanadoo.fr (J.-S. Ménoreau).

Service providers in the disability sector must take account of the special needs of these clients. This new vision of disability implies the need to recognize and respect the residents' rights to sexuality, intimacy and private life. Staff and management of care homes for the intellectually disabled must adopt a new attitude and a new way of approaching the subject of sexuality in order to better fit the sexual lives of these patients and meet their sexual needs, whilst respecting their dignity and life within a community.

Ideas and practices about the sexual habits of the mentally disabled have evolved over past decades (Lang, 1992), moving from total exclusion of sexuality to its normalization. Before the 60s, efforts were made to repress the expression of sexuality amongst this population by banning it

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altogether. During the 60s, a new movement appeared asking for the recognition of rights of the disabled to express their sexuality in as a normal way as possible. Now, both parents and carers have the duty to take into account the sexual life of any intellectually disabled person in their care, and be responsible for his/her sexual activities if they are not considered able to do so themselves. They must manage the whole issue of sex for the person and take decisions on his/her behalf in order to protect them from the dangers associated with sexual practices. The main stakeholders involved are the parents and service providers: the intellectually disabled person must comply with their instructions, often without being given any information or opportunity for discussion. [Louise Archambault's movie "Gabrielle" of 2013](#) is a good illustration of this type of situation, showing a young disabled man whose intrusive mother refuses to let him enter into an amorous relationship. His sexual freedom is limited because his choices are restricted and determined by his mother. Managing someone else's sexuality implies that the parent or provider becomes directorial and gives priority to their project over that of the person concerned, regardless of whether it suits him/her or not.

In places where this type of management still exists, there needs to be a profound change in the mindset and practices in order to implement the support system as advocated by the legal provisions. The idea would be to go from a system of "management" to a system of "consideration" as suggested by [Kristeva \(2003\)](#). "Support care" implies helping the person, working alongside them. Supporting a disabled person means helping them to become active, listening to their desires and considering their point of view, supporting them in designing and achieving their life project ([Bartholomé and Vrancken, 2005](#)). Supporting their sexuality is a specific and individualized means of helping them deal with all the different situations that can arise in their sex life and which cause them distress. The disabled person is set at the heart of the support system. This mutation allows a change of identity for the person who, instead of being an object of care, becomes a subject of life, to quote the title of [Jean-François Malherbe's book \(2007\)](#). Instead of deciding for him, it is better to give him the knowledge enabling him to develop and fulfill his sexual life projects himself according to his potential and resources, including help provided by his friends and family. The support system involves a commitment on the part of the professional to create a relationship with the subject in the aim of making them more independent. It is a difficult position since the carer has a duty to protect the fragile and vulnerable person, thereby, obliging him sometimes to become more authoritative and practical. By giving priority to protection over independence, there is a risk that a sexuality support system might pathologize the person's sex life by implying that the patient cannot express his/her sexuality without this essential and mandatory support.

A beneficial care system for the sexuality of intellectually disabled people requires many conditions, including the involvement of many individuals, meaning that an ecosystemic vision of the project is required. Editorial constraints force us to focus on the role of the managers and carers. Supporting sexuality implies a positioning of the facility managers that could bring about institutional changes and a commitment on the part of well-trained

care staff, keen to improve the quality of sexual life of the patients. This document aims to identify these minimum requirements to guarantee the best possible levels of support for the sexuality of residential clients.

Institutional change

The role of managers of care facilities is to implement the institutional project aiming to provide global care for clients, to ensure the quality of educational and social services provided and to ensure that the rights of clients are respected at all times ([Lefèvre, 2003](#)). Awareness has been raised amongst care facility administrators about the need to provide support for sexuality to intellectually disabled clients. The media have also played a role by drawing the attention of the public to cases of sexual abuse, unwanted pregnancies and STDs amongst this population. To protect them from these risks, the need for sex education for intellectually disabled clients has been advocated in scientific conferences and published articles. These have led law makers to require care facility managers to include sexual support for clients in their institutional projects. In France for example, the law n° 2001-588 of July 4th 2001, pertaining to abortion and contraception, requires care facility managers to ensure that "information and education about sexuality and contraception are provided in all facilities for the disabled" (Article 23). This resulted in policy guidelines on the issue to be drafted by facility managers. An American study reports that 96% of administrators state that their facility has written policy guidelines about sexual abuse ([Gust et al., 2003](#)). Managers have the responsibility of ensuring that their policy is applied in order to avoid sexual problems as far as possible, and to provide support to clients when it fails. The professionals must therefore possess the tools and competences to successfully fulfill this task and adopt a positive and respectful approach to sexual life, to avoid developing a fear of sexuality amongst clients.

It is the responsibility of managers to apply all necessary measures to avoid STDs and problems related to sexuality amongst their clients. The risk of sexual abuse of an intellectually disabled client and subsequent disease or pregnancy must be avoided. Many initiatives can be taken in the aim of upholding the clients' rights to a risk-free sex life, but promotion of their sexual health is not limited to the prevention of sexually-related problems, with a protective attitude alone. The [WHO \(2006\)](#) considers that "sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality: it is not merely the absence of disease, dysfunction or infirmity". The sexual well-being of residential clients requires activities and projects that complicate the measures taken for prevention. In their inspection report on the sterilization of disabled persons, [Lagardère et al. \(1998\)](#) state that the loving and erotic fulfillment of these clients requires the availability of a suitable environment providing the means to preserve intimacy, a legal framework (rules) and well-trained staff.

The involvement of care facility managers is crucial in giving impetus to a movement of awareness and mobilization to promote the quality of sexual life for the intellectually disabled. Their role puts them in an ideal position to lead their facilities in the direction of change for the better, by

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