

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

# Sexuality in Rehabilitation: Supporting Canadian Practitioners Conceptually Towards Client Enablement

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## Résumé

Cet article explore les nombreuses dimensions du sexe qui entraînent de très fortes réactions morales et éthiques. Pour soutenir les praticiens qui souhaitent se sentir plus à l'aise et compétents pour discuter de questions sexuelles, l'article introduit un modèle de pratique conceptuel hybride. Combinant un modèle issu à l'origine de la sexologie et un autre de l'ergothérapie, le *Ex-PLISSIT Enablement Model* offre un cadre souple et progressif permettant d'orienter les praticiens vers un plan qui leur permettra de mieux comprendre et de travailler dans leur propre champ d'application tout en évaluant si les clients sont prêts et disposés à s'engager dans le sujet à des degrés divers.

## Mots clés

incapacité, habilitation, éthique, modèle, ergothérapie, réadaptation, sexualité

## Abstract

This article explores the many dimensions of sex which result in very strong moral and ethical responses. In support of practitioners who wish to feel more comfortable and competent discussing sexual matters, the article then introduces a hybrid conceptual model of practice. Combining one model originally from sexology and another from occupational therapy, the *Ex-PLISSIT Enablement Model* offers a flexible, progressively-staged framework to guide practitioners toward a plan to better understand and work within their own scope while also assessing if clients are ready and willing to engage with the subject to varying degrees.

## Keywords

disability, enablement, ethics, model, occupational therapy, rehabilitation, sexuality

## Introduction

Sexuality and sexual expression can be disrupted to varying degrees for many individuals receiving rehabilitation services [1,2,3]. They often, though, receive a limited and conflicted embrace in rehabilitation practice. Consider the following situations:

Mavis and Harry have been married for fifty-three years. Harry lives in a nursing home and Mavis visits him every day. Six months ago, Harry experienced a stroke and now uses a wheelchair for mobility, still requiring assistance for all transfers. Communication is compromised by expressive aphasia. Decision-making falls to Mavis, with Harry's assent and dissent being central to that process wherever possible. Mavis has asked the physiotherapist if Harry might soon be able to independently transfer from chair to bed, so that they can enjoy "a bit of cuddly time together" during her visits, without having to involve the staff.

George is 32 and has lived with a spinal injury for the past 8 years. During an assessment for a new mobility device, he suddenly asks the occupational therapist "Do you think I will ever be able to masturbate properly again? I'll certainly never find a boyfriend again."

Amita is a young high school student who also lives with Trisomy 21. The school occupational therapist has just learned that Amita recently become involved with the police after a complaint was made about apparent lewd behaviour involving Amita and another student in a public area near the school. The school staff were unaware of any particular connection between the two students.

These fictional stories are derived from the common experiences of rehabilitation practitioners across many domains. They are also similar to some of the stories, of varying complexity, that end up playing out in the media in high profile cases. The story of Henry and Donna Lou Rayhons [4] is one example where a husband is suspected of sexual assault because his wife's dementia is considered to render her incapable of giving consent. Equally, the story of Anna Stubblefield and DJ [5] raises similar questions in a different context, with related concerns about capacity to consent and potential for influence or lack of clarity in communications. Less controversial for many was the story of Sandra Day-O'Connor's husband, John [6,7], becoming 'involved' with a co-resident at his long-term care home. Less known but perhaps more challenging in some ways was the story of Tyrann and Leanne [8], teenage students at a school for people with disabilities where policy [9] explicitly supported their sexual relationship.

These stories probably give rise to different reactions among different readers. In the experience of the authors, responses from practitioners can involve passionate advocacy for clients' right to sexual expression – as is evidenced by the ongoing work of the Sexual Health and Disability Alliance (SHADA) [10] in the United Kingdom, and its nascent global counterpart SHADA International [11]. For many, though, their response is deeply rooted in a reflexive sense of 'yuck', the instinctive feeling of discomfort experienced when presented with an unsettling idea or practice, often resulting in a sense of fear [12]. In matters of sexuality, it is dependent upon the individual(s) and the circumstances in each situation such as the extent to which one must discuss precise details of sexual acts in order to determine solutions. Many feel sexuality is simply not something to discuss in general, and more especially in the detail required to explore different positioning or the use or adaptation of assistive devices<sup>1</sup>. These latter topics might seem beyond one's own experience, thus placing them beyond one's imagination. Some

<sup>1</sup> To experience what this might be like more realistically, this online video [Prends-Moi](#) is a good start.



people are more able to talk of sexuality and sexual expression with individuals who seem like peers, while others feel acutely uncomfortable or unnerved discussing these matters with anyone they might also find attractive. Some practitioners wish they could respond more effectively, but many potential discomforts lead them to avoid the matter – from those factors just described, to more simple uncertainties about this being part of one's role, to lack of confidence that they can actually be helpful or feeling at a loss to help at all given a client's situation and circumstances. In too many instances, many practitioners might hope the issues will disappear or be addressed by someone else.

Possibly one of the most disappointing aspects of typical practitioner responses is the gap between the recognition of a legitimate matter that might benefit from professional support toward enablement of specific goals and the paucity of such enablement in practice at large. This tendency to see the clients' concerns but do little to address them plays out in anecdote after anecdote, but has also been demonstrated in a number of studies [3,13,14], including two recent unpublished surveys [15,16] presented at the 2017 annual conference of the Canadian Association of Occupational Therapists. Given the intimate multi-dimensional relationship between personal identity and one's own sense of right and wrong, between comfort with one's own sexuality and individual preferences and limitations around acceptable sexual expression, it is understandable that practitioners and clients alike may feel uncomfortable with the topic and even avoid it altogether. However, it is also clear that many clients wish to discuss matters of sexual expression but are reluctant to raise the topic [17,18]. This suggests they are relying on practitioners to open the discussion so that an opportunity to bring it into the open is offered. Clients can then respond depending on their own wishes – take the opportunity, leave it until later or not include it in rehabilitation.

One might ask, "Why make the effort to address sexuality at all?" The answers would appear to start with the fact that most people want to be sexually active and can face certain challenges which might be overcome with the appropriate support [19,20]. Beyond that, sex has the possibility to make a contribution to health and well-being of all individuals [21,22]. From an occupational therapy perspective, sexuality and sexual expression interact in the emotional, physical, cognitive, and spiritual domains of a person to improve health [23], well-being [24] and quality of life [25]. The American Occupational Therapy Association has decidedly dispelled any questions about the place of human sexuality within the domain of occupational therapy practice with its inclusion in their practice framework [26]. Equally, the contributions of all rehabilitation practitioners may be essential to enabling sexuality for clients. Speech and language pathologists might offer strategies for dealing with communication challenges, and in some situations, swallowing difficulties. Physiotherapists are often involved in strengthening the pelvic floor to improve continence, but any musculoskeletal problem can easily lead to difficulties in finding comfortable positions for sexual activity. Rehabilitation nurses may help with any range of concerns from stoma and other wound care to diabetes and pain management.

We wish to assert that such work is a critical part of rehabilitation practice – insofar as the goal of enabling engagement and participation also includes enabling sexual expression, and thus all practitioners have a role in validating a client's wish to be sexually active, and to support this directly or through referral to others. To that end, this article explores the many dimensions of sex that result in very strong moral and ethical responses, including the matter of sexuality and its uncertain place in rehabilitation practice. Presented in three sections, the article offers an overview of the range of factors that make sexuality a particularly sensitive clinical domain. In the first segment, it is proposed that individual perspectives and experiences play a significant role in limiting the embrace of sexuality as part of practice. The second segment examines some of the societal constructs that can complicate practice and disable practitioners by making the topic layered and nuanced to the point of instilling fear of making any attempts to help – legal frameworks, practice standards, policy and procedure, scope and competence concerns as well as moral and religious prejudgments. In both of these segments, some discussion will be focused on separating the relevant considerations from those that may not actually apply. This clarification of uncertainties and relevancies can lead the way to a more reflective principle-based approach to developing options for next steps in practice.

The final segment will introduce a hybrid evolution of two extant conceptual models of practice. Across health care, conceptual models of practice have been developed as an approach to frame and improve our understanding of a discipline and to guide its practice. However, we recognize inherent weaknesses in the use of models, as has been discussed from various angles in a range of disciplines<sup>2</sup>. For regulated professionals, however, conceptual models are a familiar tool that assist with shared understanding of complex dimensions of their interventions and offer practice guidance that can be evidently aligned with their regulated scope and standards.

The evolved model presented here brings together one originating from sexology and another specific to occupational therapy. The resulting conceptual model can be adapted to incorporate elements from other professional practice domains. This evolved model is intended to give additional support to practitioners in order to consider the real possibility that they can take calculated risks and broach matters of sexuality and sexual expression with their clients. It is hoped that this will be seen as a legitimate involvement for any practitioner.

<sup>2</sup> The debate around the proven effectiveness of models in practice is larger than could be addressed here. We recognize that commonly discussed weaknesses include the lack of an agreed lexicon [27], and the existence of different or even conflicting models attempting to explain the same domain very differently [28,29]. Given this, some authors propose tentative models [30] while others address their perception of the shortcomings of extant models [31]. It is with this always in mind that we adopt the position that models can be useful but are always open for improvement.

## Individual Attitudes, Public Responsibilities

In ethics practice, the notion of the 'yuck factor' can be used to describe the initial gut response to the feeling that something is no longer within the realm of the comfortable. Such feelings are regularly encountered in healthcare practice as a sense that all is not clear, morally or ethically<sup>3</sup>. It is readily imaginable how the scenarios described at the outset can inspire an immediate sense of unease for many, albeit to varying degrees and for varying reasons. These feelings do not always endure, however; they can give way to more reflective reasoning that tames initial reflexive responses. Healthcare practitioners generally have higher duties assigned to their roles, including the management of their own feelings of unease in the service of meeting client needs. With matters involving moral unease, deeper reflective reasoning about the source of unease and examination of one's own values are critical to serving clients' needs in various situations. Facing the dying and death of a client or adopting non-judgemental attitudes about smoking or eating habits are common examples. Sexual matters trigger similar need for reflection about client needs versus practitioner needs, with the latter taking a lesser priority in many situations. Thus, the role of healthcare practitioner is one that regularly demands deeper personal moral reflection to ensure ethically defensible practice.

These individual responses to sexual matters are best understood in their broader context, recognizing that this context will have had differing effects on each of us. Our personal morals are shaped by our families and cultures, experiences with faith-based teaching (formal or informal), exposure to friends and acquaintances, and happenstance encounters with other people and ideas. Because ideas about and experience of sexuality are so profoundly influenced by personal values and individual beliefs, they also, in turn, tend to link to one's personal identity and sense of self. These influences and effects are far from universal, and often unpredictable. They are a function of individual upbringing and subsequent experiences of and perspectives about sexuality and sexual expression that lead to individual attitudes and judgements on sexual matters.

Individual sexual interests and activities can vary dramatically. Thus, in potentially opening the door to a client discussing sexual matters, one opens the door to a conversation that may delve into ideas about which one has very little experience or significantly differing values. Ideas that may or may not be shared include the simple proposition that sex can be pursued for just the pleasure of it – independent of procreative aims. Ideas of monogamy, polyandry [32], sex toys, masturbation, fetish play and a host of other pursuits [33] might arise. In addition, sex tends to become enmeshed in thoughts about love, vulnerability, body image, longing, lust and the potentially unsettling reality of discussing certain body parts and their functions. Things commonly labelled as 'deviant' may crop up – requiring one to suspend the tendency to make judgements and remain client-centred, despite any attendant discomfort.

More common to everyday practice, rehabilitation practitioners would typically be expected to discuss various body parts and their functions as part of assessing and enabling independence. This includes very intimate matters of passing urine and feces, as well maintaining the hygiene of the groin (that catch all term for the labia, clitoris, penis, foreskin and scrotum) and the anus and its environs. While these are often discussed in discreet and professional ways in the context of personal care, they tend to acquire a different sort of flavour when the talk is about sex – the conversation may not be as straightforward as when one discusses the typical notions of activities of daily living.

Curiously, although it often appears that sex is ever more present in our society at large due to its regularly evident positioning in advertising, entertainment and even politics, honest and open conversations about one's own sexuality and sexual expression tend to be rare. When they do happen, they may more often be easier with relative strangers (which is what therapists are at first) or with a very few close friends. Talking about one's own sexual desires remains a tricky thing for many people...even with their sexual partners [34]. However, those ideas, experiences and practices that might be part of one's private life, perhaps only one's fantasy life, remain in the private realm – leaving the shared social realm characterized by more restricted conversations about sexual expression. It is arguably rarer still to have frank discussions about sexual expression between parents and their adult children. Indeed, one author suggests that it is common for family to think of parents, mothers especially, as embodiments of holiness when it comes to sex [35].

There is, nevertheless, a trend toward more openness. Laws and attitudes have evolved to move some societies away from these very limited views on the norms of human sexuality [36]. In general, over time, there is an evidently wider embrace of some diverse sexualities and sexual identities in healthcare practice [37]. This openness may fall short in the experience of many individuals living with differing physical and cognitive abilities [38-40] – perhaps owing to those same Victorian values and the 'desexualizing' of individuals who live with disabilities that is still very evident in some societies [41]. These often manifest as commonly held myths and biases about persons with disabilities and older people and sex [34,42,43].

A further concern is the straightforward fear of sex given the elements of risk that accompany many aspects of sexual expression. Even solitary masturbation can be 'risky' if there is the possibility of unwanted discovery – something that exists in many shared living arrangements, both permanent (like family or communal/congregate living) or temporary (like hospitals and rehabilitation centres). Engaging in sexual expression with others carries risks of infections, tissue damage and pregnancy. These are generally manageable through education, prevention and treatment where needed.

<sup>3</sup> The two terms 'morals' and 'ethics' are used here with a recognition that they are often used interchangeably. While no widely accepted distinction is typically made in the literature, we use 'morals' here to refer to more personal reflexive responses to questions of right and wrong and the term 'ethics' to refer to more collectively deliberated ideas of what is right and wrong. These latter ethical notions are then found in law, professional ethics codes and standards as well as in much of our generally accepted social conduct – though they can remain the subject of debate and disagreement.

The other big risks are associated with emotions and self-esteem – rejection, disappointment, embarrassment, shame, disillusionment, and failure. These may be experienced by anyone seeking to engage in sexual expression<sup>4</sup>. For most clients, however, these can be minimized and managed, and ‘treated’ as necessary. For a very small few, sex may indeed be contraindicated, potentially sustaining or exacerbating signs and symptoms that other interventions are seeking to diminish. For example, cardiac concerns may be a legitimate reason for counselling a couple about restricting their sexual activity even though their relationship may be severely affected [44]. For another group of clients, sexuality and sexual expression may simply be a matter they prefer not to explore. It may be because a person identifies as asexual, or because they are not comfortable with the matter – despite a practitioner’s awareness of clear concerns that may have simple solutions.

Discussing matters of sexuality and sexual expression can also present other more personal ‘risks’ to practitioners themselves. The very close ties to one’s own moral, physical, emotional and spiritual self can intensify the sense of ethical sensitivity and the prospect of discomfort and unease involving any or all of these domains of self if the topic should need to be explored openly. These biases and fears can then be further complicated by the responsibilities and expectations that may accompany any role as a healthcare practitioner. A multitude of questions can overwhelm even the most passionate healthcare provider who considers the enabling of sexual expression to be an important part of their role, when pondering the potential risks in those client stories described above:

- What kind of quality of life are Mavis and Harry allowed in their later years?
- Is there any hope for sustaining their love of cuddling? Is cuddling ‘sex’?
- What threshold of consent does it require?
- What other expressions of ‘closeness’ are acceptable?
- What would be a legitimate goal and plan of treatment for George who is seeking to masturbate more effectively?
- How would one facilitate George’s capacity to achieve his goal, and the sub-goals leading to it?
- What would appropriate documentation look like?
- What is ‘right’ when a new love or lust interest seems a benefit for a person like Amita whose cognitive capacities may be limited?
- What if that person’s family sees it as an affront to their notions of what is right or good?
- When can a practitioner help a teenager like Amita, or someone with cerebral palsy, begin to explore their own sexuality, and within what limits?

Deciphering what possibilities and limitations might be defensible in healthcare practice becomes complicated work.

There is one further fearful complication to consider. Sexuality involves both erotic and sensual elements, but these are distinct and are not necessarily of the same order. They can be related, but can also be largely independent of each other in many instances. Sensuality can be enjoyed without any sexual dimension. Things like a head and neck massage, warmly embracing a child or good friend, having one’s hair cut or styled and even everyday care activities like a sponge bath may involve a degree of sensuality – without a *necessarily* sexual association. There is, however, always the possibility that such partly sensual things might give rise to the sexual for one party but not the other, or for both where this would be inappropriate. This overlap may be one of the reasons for the high sensitivity around all things sexual in rehabilitation – the prevailing risk of misunderstandings or perception of transgression of professional boundaries within a realm of great delicacy and potential legal gravity.

Many of the concerns raised above can be largely resolved through deeper reflection on the sources of one’s unease and fear. That unease can often be effectively managed through continuing professional development and furthering one’s understanding of addressing sexuality through the growing literature on sexual enablement [19,45,46]. Guidelines and practice standards can be signposts, along with codes of ethics and connecting with peers and professional bodies for further support. Many of the main elements of these signposts speak to issues centrally associated with sexuality and sexual expression – consent, professional boundaries, sexual abuse, judgement, trust and respect. This can also mean such guidelines will give rise to caution among health care providers about meeting these professional expectations, and the possibility of being perceived to fall short of them. This could even happen inadvertently or unintentionally through misunderstanding or misinterpretation of our words, intent or actions. Ultimately, though, these anxieties need to be overcome as one can only become more competent in managing these concerns through the experience of ‘doing’ – taking the plunge and opening the discussion of sexuality and sexual expression with one client, and then another. Robust reflection on every experience will maximize the learning and skill that can be garnered from each and applied to the next.

For many who wish to include matters of sexuality among those they will address with clients, and who feel able to begin to do so, prevailing uncertainties about the legal context and the basic parameters for practice can present significant barriers. With this in mind, the next section will focus on providing some clarification of the legal concepts and contexts as is possible given their variability across jurisdictions. Readers are always advised to confirm the legalities within their own jurisdictions.

<sup>4</sup> One vivid example of this is found in the short film [Bedding Andrew](#).

## Private Matters, Public Parameters

To help with understanding more of the complex practice context in which issues of sexuality are encountered, three domains will be discussed: definition of terms; legal contexts; and clinical uncertainties.

Defining terms is always important. The World Health Organization (WHO) has defined sexual health as “a state of physical, mental and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence” [48, p.5]. This definition highlights many key factors that are of significance to rehabilitation practitioners – well-being, a positive approach, respect, pleasure, safety, coercion, discrimination and violence/harm. These factors can also arise in other decision-making issues in healthcare, which suggests that much of the concern associated with sexual expression is familiar to practitioners, albeit within different clinical contexts.

In the same report, the WHO states that sexuality is:

...a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and *expressed* in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships. *While sexuality can include all of these dimensions, not all of them are always experienced or expressed.* Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors [48, p.5]. (*Emphases added*)

This broad definition speaks to two particularly noteworthy elements. The mention of ‘throughout life’ aligns with the scope of most rehabilitation practitioners’ perspectives. The qualifier ‘not all’ speaks to the notion of client-centred practice – any person’s sexuality and sexual expressions are individual subsets of the overall realm of the sexually possible. Thus when working with people who are living with disabilities and the effects of ageing, obtaining clear information about each person’s preferences for sexual expression is a cornerstone of enabling and supporting ongoing sexual health. These definitions can offer an inclusive and affirming first point of clarity when discussing most matters of sexuality and sexual expression. Furthermore, while sexual matters may be peppered with ethical dimensions, the ethics infusing sexuality and sexual expression are not unique while the benefits that arise from sexual expression might not be found elsewhere [49].

There are, of course, some clear legal limitations on sexual expression. Laws are critical elements of the boundaries of practice, but are often poorly understood by practitioners. In Canada, for example, the age of consent is a complex legal construct – there are multiple ages of consent beginning at 12 years of age, and dependent on the age of the other party as well as the potential for the relationship to include some dimension of trust in or authority of one person vis à vis the other [50]. Fortunately, the details of this very legal concept can be clarified at any point at which they become pertinent.

Sexual consent laws vary from one jurisdiction to another. For the purposes of this paper, the concept of capacity is taken from the *Health Care Consent Act, 1996* [51] in Ontario. It first assumes decision-making capacity, unless there are ‘reasonable grounds’ to question it. Then it adopts a two-pronged concept of capacity – the ability to understand the relevant information and the ability to appreciate its relevance to oneself.

In Canada, a relatively recent Supreme Court of Canada decision [52] involved individuals who were neither disabled nor aged. This decision did, however, become relevant to all situations of consent to sexual activity. It determined that one cannot pre-consent to sexual activity – this must happen at the time of the sexual interaction and also requires ongoing informed voluntary consent. This is particularly pertinent as it reiterates that when discussing issues around clients and their potential consensual sexual activity, regard must be given to whether there are reasonable grounds to question the client’s capacity to give consent to different types of shared sexual expression. This legal decision also precludes any form of ‘prior consent’ to sexual activity when one might anticipate becoming decisionally incapable of consenting in the future – thus no Power of Attorney for Personal Care, no advance care plan, nor any proxy decision maker of any sort can suffice as valid consent at any point. Further complexity ensues with the variations that may follow: fluctuating capacity; neurodegenerative conditions that erode decisional capacity; cognitive development and learning that lead to emerging capacity; and differing thresholds of ability for understanding and appreciation with respect to one sexual act or another.

While these current legal parameters are clear, there has been some valuable ethical pondering about this judgement being potentially unjust for some individuals. The prohibition of sexual activity whenever a person is deemed unable to consent can mean that many who would evidently assent are still denied any chance to experience the benefits of sexual expression. Many long-term intimate partnerships continue into older age and it is common for one partner to develop dementia. If a particular practitioner feels that the person living with dementia is lacking the ability to understand or appreciate any of the many dimensions of sexual activity, they may declare them incapable for such decision making and create a situation where an otherwise loving intimate relationship of decades must abruptly cease in various respects. Debating this as a matter of potential injustice raises the possibility (were the law to be changed) of enabling some form of assent to sexual expression and activity [53]. For the time being, however, this is a moot point for any such situations in rehabilitation practice where capacity to consent would still be legally essential.

More immediately relevant are two related notions that arise when one ponders the practitioner's role in enabling sexual expression. Firstly, the evaluation of capacity is of the utmost importance. The *enabling* of capacity to consent to sexual activity might be a possibility, much like good practitioners seek to enable capacity to make other treatment or property decisions, rather than settling for the simplicity of a finding of incapacity. Secondly, distinguishing between healthy *sensual* experiences and those that might be problematically sexual is paramount, otherwise people may be deprived of almost all tactile stimulation and physical intimacy, because of that lurking 'yuck'. This requires some thinking and personal reflection and hopefully some desensitizing of caregivers about the taboo of touch, which is often avoided in care contexts except for the most basic pragmatics of personal hygiene. Getting past this sense of the taboo will likely require some open discussion among practitioners about their own perspectives on sexuality and sensuality and the boundaries between the two. Once that happens, the tricky issue of evaluating consent can help direct the next steps in the enabling, if that is the direction chosen. To this end, the next section offers some thoughts about what sort of criteria might be used to help gauge the evaluation of capacity to consent to sexual activities.

## Evaluating Sexual Decision-Making Capacity

The abilities and knowledge base identified in Box 1 are among those proposed as criteria [54] for evaluating capacity for sexual decision-making. These criteria are far from universally accepted, and they may not align with the requirements for consent in some jurisdictions, but they do offer a good starting point. Other approaches to evaluating capacity for sexual decision-making are offered elsewhere [55-57].

### Box 1

#### Suggested Criteria for Evaluating Sexual Decision-Making Capacity

- Have basic sexual knowledge, such as the relevant female and/or male anatomy and function.
- Knowledge of the nature of relevant sexual activities.
- Understand the possible consequences, including risks, of the sexual activity to themselves and their partners.
- Have the ability to understand appropriate and inappropriate locations and times for sexual activity.
- Possess the ability to express a personal choice and to resist coercion.
- Possess the ability to recognize distress or refusal in a partner and stop the activity.

Adapted from Vancouver Coastal Health Authority [54]

One should be cautious when considering these criteria. While the concepts of capacity and consent are important, the potential for something meaningful related to sexual activity being lost or taken away is a real risk if an individual does not appear to meet one or more of the criteria. It is critical here to remember that the threshold for decisions about affectionate behaviour like cuddling or embracing is different to that for more sensual kissing, and different again for anything more sexually involved such as mutual masturbation, oral sex or penetrative sex.

Most importantly, it is imperative to remember that the criteria can also be used for the purposes of *enabling* capacity. By identifying more precisely where abilities to understand and appreciate have not been demonstrated, one can then focus efforts on improving them, including:

- Education in any realm of knowledge considered essential.
- Using varied formats for conveying required information.
- Paying attention to the use of plain language rather than medical terms and jargon.
- Assisting with identification and minimization of risks by giving consideration to the details of each client's context and situation – and then further discussing issues of privacy, offering suggestions around lubricants or toys and preventing sexually transmitted infections.
- Ongoing evaluation and enablement as appropriate.
- Monitoring any fluctuations in functional and decision-making capacities and working within these variations to access abilities when they are at their best.

These are just a few of the generic suggestions from among the broad array of possible professional approaches and techniques that might be employed given the specifics of any individual client's situation.

It is worthwhile to return briefly to the notion of fear at this point. The deeply nuanced complexities of sexual expression and related decision-making as outlined in the law can be enough to instill dread and panic in those venturing into the work of sexual enablement. It is critical to reflect on the fact that for many clients, decision-making capacity will not be an issue in any way – there will be no reasonable grounds to question capacity. For those where it might be a consideration, the criteria above can act as guideposts and are only one resource among many. Team members, other colleagues, regulatory bodies, and other support and advocacy organizations and the tools they create are valuable resources to pursue.

To assist practitioners further when approaching something as complex and value laden as sexuality and sexual expression, it is often helpful to consider conceptual models and practice specific tools. After briefly introducing other relevant existing conceptual models of practice, they will be merged to offer a tool tailored to assist with creating intervention plans that recognize the comfort and competence of both clients and practitioners.

## The Evolution of a Conceptual Model of Practice

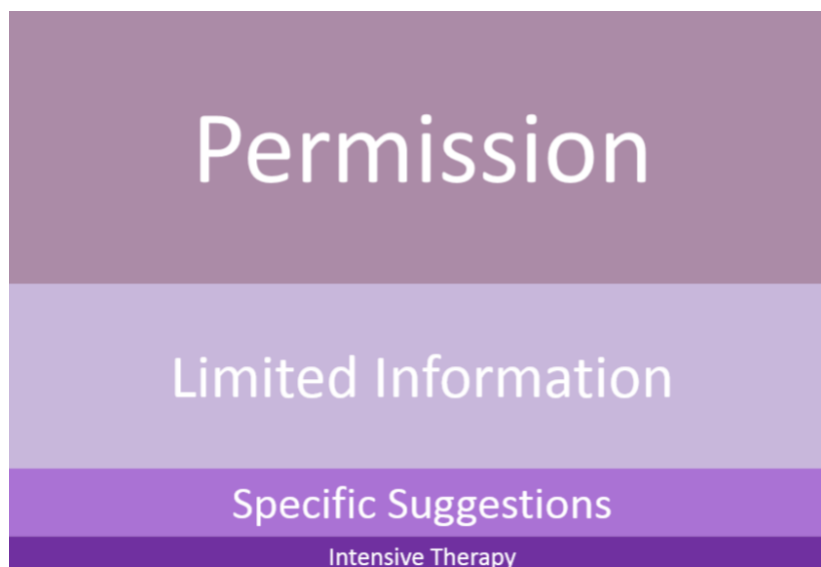
The final section outlines the existing models that have been combined to create a new hybrid conceptual model of practice. This evolved model has the potential to offer more specific practice guidance for clinicians aiming to engage with the enablement of clients' sexuality and sexual expression.

### The PLISSIT and Ex-PLISSIT Models

From the realm of sexology comes the PLISSIT model. The acronym derives from the four levels of intervening described in the model: permission; limited information; specific suggestions; and intensive therapy [58]. The names of each level are largely self-explanatory. 'Permission' involves giving permission to talk about sexuality and sexual expression and the challenges experienced around them. Sometimes 'permission' might include simple permission to be sexual in the first place. Not everyone is supported to feel expressly 'allowed' to be sexual as they grow and develop. 'Limited information' may involve an explanation of how some sex-related anatomy works or clarification of the effects of certain physical differences or medication-related side effects. It may also involve providing details about potentially useful resources – books, web-based information and support, retail sources for assistive devices and other items or the contact details for an advocacy group or professional services. 'Specific suggestions' can entail exploring ideas for adapting toys and other devices, positioning possibilities that mitigate any functional limitations and proposals for policy, education and other changes that will make an organization and its physical environment more sex-positive. 'Intensive therapy' is limited to the sorts of interventions that would only follow after a practitioner completes relevant professional development activities that afford the knowledge and skills to intervene at this more profound level. Referral to a particular specialist practitioner might be one of the 'specific suggestions' offered. As previously noted, there is a need for critical consideration of any model, including PLISSIT. However, recent evaluation studies suggest an emerging evidence base examining the usefulness of PLISSIT in supporting specific groups of people to overcome some forms of sexual dysfunction [59,60].

One aspect of the original graphic representation of the PLISSIT model is the indication of the proportion of clients whose concerns are likely to be resolved with each level of support to deal with their concerns. The majority will require little more than permission. Thus, the practitioner ought to find ways and opportunities to convey an openness to discussing matters of sexuality, but at the same time be mindful of individual preferences and norms about such discussions. Of those who need more than permission, most will benefit adequately from simply be providing with limited information; a small remainder will need specific suggestions; and only a very few will have to consider intensive therapy [61]. Figure 1 captures the idea of the proportion of clients requiring each level of support.

Figure 1: The PLISSIT Model



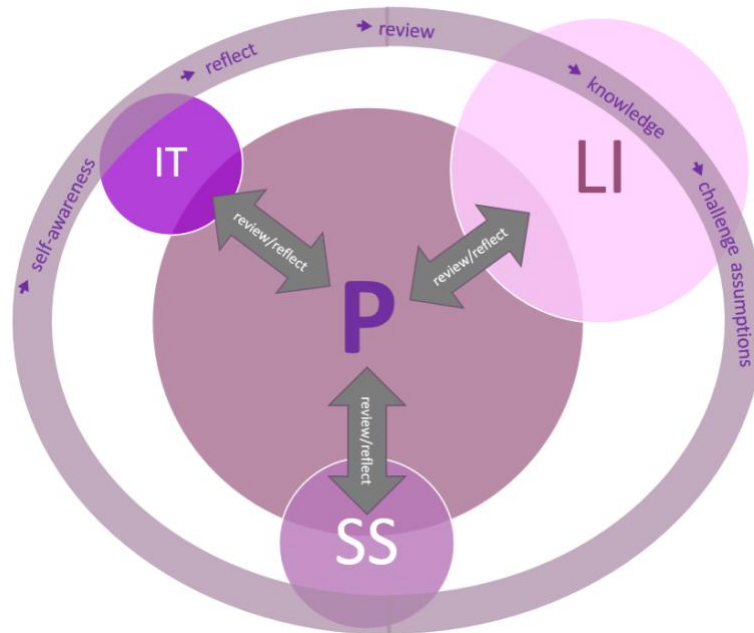
Adapted from Annon [58]

More importantly, for non-sexologists, the same proportions could apply to the proportion of practitioners who *ought* to feel it is within their scope to assist at each level. Most everyone will be able to give permission and work at that level with most

clients; many practitioners ought to be able to offer limited information; some more informed/experienced practitioners will be able to make specific suggestions; and only a very few will be prepared for intensive sex therapy. This last group would typically have undertaken additional professional development and probably pursue relevant specialist certification.

Davis and Taylor [62] further developed PLISSIT with the introduction of reflection and review at every point where you consider moving from one level of involvement to another, with the need to return to the 'P' stage and gain permission from the client to move to another stage. Their adaptation also recognizes that one might move back and forth between the levels or stages; the process need not be seen as a simple linear progression. They called their adaptation the Extended PLISSIT approach (Figure 2) – or, Ex-PLISSIT for short. Their revised graphic representation highlights the need for ongoing attention to self-awareness, reflection, review, knowledge and challenging assumptions.

Figure 2: The Ex-PLISSIT Approach



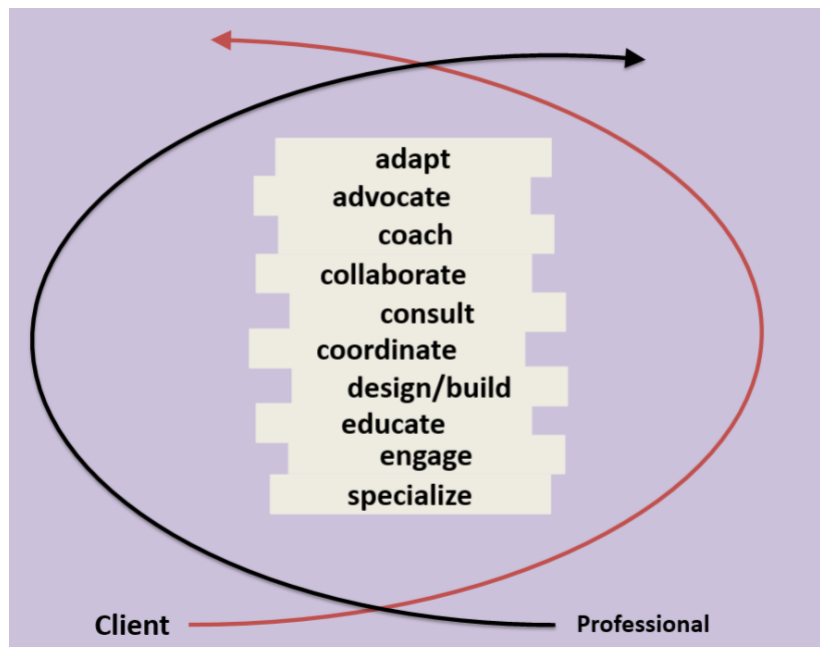
Adapted from Davis and Taylor [62]

### The Canadian Model of Client-Centred Enablement

The Canadian Model of Client-Centred Enablement (CMCE) [63] (Figure 3) identifies skills and approaches within a collaborative process enabling individuals, groups, agencies, or organizations to have the means and opportunity to participate in shaping their own lives. The skills and approaches it identifies include: engage, coach, advocate, educate, collaborate, consult, coordinate, design/build, adapt, and specialize. Although it emerged from an occupational therapy perspective, practitioners from multiple disciplines can potentially find it useful. Part of its intuitively useful nature is that it makes visually explicit many aspects of rehabilitation practice that are implicit in work with clients [64]. These aspects of practice include the interactive relationship between client and therapist, the array of enablement skills that might be applied with clients, their families, co-residents, care staff and even with the more structural or administrative dimensions of an organization, including the board, senior management, policy and procedure and the allocation and layout of spaces, assistive devices and other resources. Like many conceptual models of practice, the CMCE diagram captures these elements and presents them as a reminder of both the expectations and the options that exist.



**Figure 3: The Canadian Model of Client-Centred Enablement**



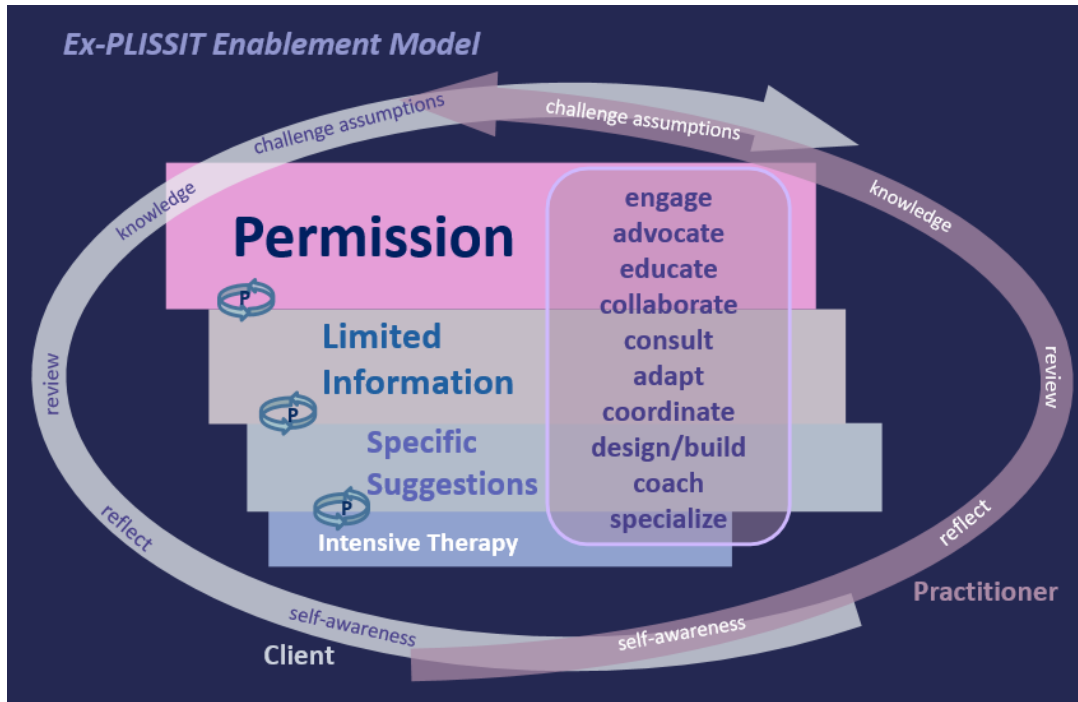
Adapted from Townsend et al. [63]

The CMCE skills list also includes those relevant to the broader context of practice relevant to rehabilitation clients – organizations and their administrative, policy and physical environment dimensions. These are important areas for intervention and adaptation. Improvements in these areas can be environmental (layout, use of designated spaces and equipment resources), procedural (policy development or revision, guidelines and protocols) and attitudinal (mission, vision and values and the tone, stated purpose and principled foundations of policy and procedure).

**The Ex-PLISSIT Enablement Model**

By combining these two models, the CMCE and Ex-PLISSIT, a tool emerges that serves to remind practitioners of the stages or levels of engagement, while also suggesting some of the specific enabling skills and approaches to employ in each. This hybrid model is the Ex-PLISSIT Enablement Model (EPE) (Figure 4). The need for reflection at regular points in the process is captured by the small circular arrows between each level, with ‘P’ indicating one may need to seek permission to move to the next more involved level of interventions or recommendations. The collaborative nature of the process is captured in the larger arrows, where those ongoing considerations of self-awareness, reflection, review, knowledge and challenging assumptions are represented for both client and therapist.

Figure 4: The Ex-PLISSIT Enablement Model



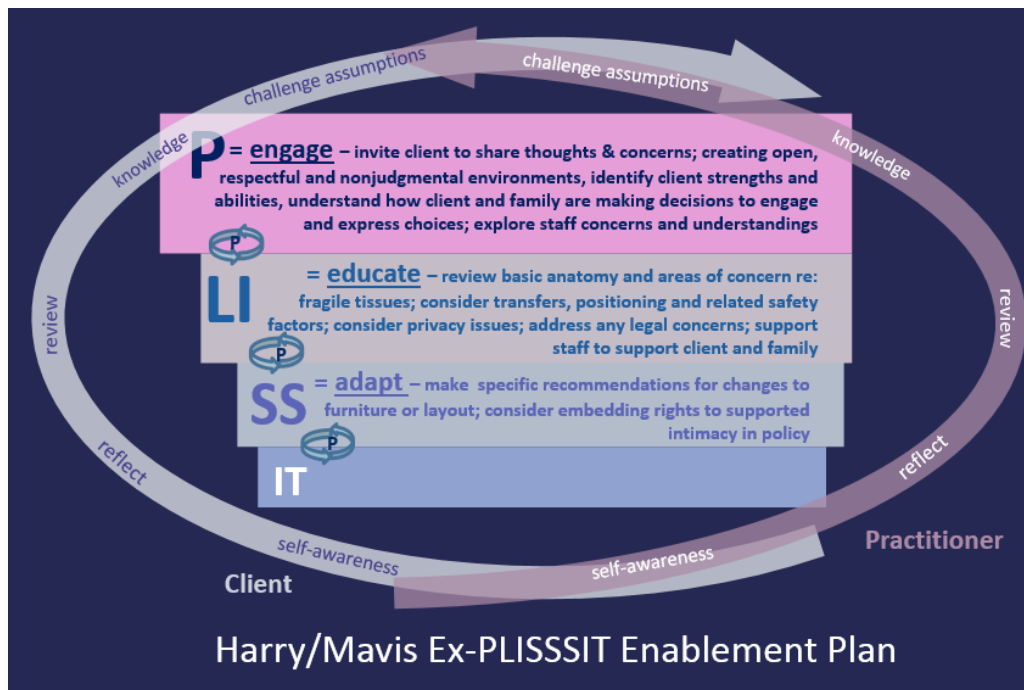
Rather than avoiding the discomfort of sex discussions, practitioners should seek to improve their own awareness, competence and comfort with the relevant skills that can be employed at each level in the EPE model. Equally, the inevitable encounter with each individual’s values, ethical awareness and sensitivity are critical to addressing sexuality and sexual expression. Only when one is in tune with one’s own values around sensitive topics can one assist others to explore them.

Using such models as tools, practitioners can support dignity, autonomy and flourishing in the lives of others by:

- Gauging the practitioner’s own competence to address issues of sexuality and sexual expression, and improving upon it over time;
- Gauging clients’ readiness and capacity to address sexual matters;
- Collaborating with others to ensure clients’ needs are addressed; and
- Educating and advocating for attitudinal change among family and service practitioners as well as across whole organizations.

The EPE Model can be used to develop individualized plans using selected intervention approaches at the relevant levels. For Mavis and Harry (the fictional couple mentioned at the start of this article), ‘permission’ might involve an affirmation of the legitimacy and value of the intimacy Mavis is seeking. It may also involve gauging Harry’s willingness to share that intimate time, and how they prefer to spend it, when and where. ‘Limited information’ would involve identifying any potential risks of harm – e.g. falls, strains, positioning-related concerns – so that they can be discussed and mitigated. Efforts may also need to be made to enable staff to appreciate what is being requested, what it does not necessarily involve and to understand and address their concerns about the idea and any plan to make it happen. ‘Specific suggestions’ may not be needed, but could include any changes to the furnishings or layout to enable cuddling more safely and comfortably. Individual situations can illuminate changes to policy and common practices that might need to be considered universally across the organization and potentially for all clients. Such a plan for the story of Mavis and Harry might be graphically represented as in Figure 5.

Figure 5: An Ex-PLISSIT Enablement Plan



As previously identified, one of the biggest challenges in addressing the issue of intimacy in individuals with cognitive impairment is decision-making capacity. Using the EPE Model as a guide, one can approach this challenge at every level. Offering permission to discuss sexuality and sexual expression and to affirm an individual as a sexual being does not *necessarily* lead to anything that would require consent. It does, however, convey a dignity-enhancing appreciation of the client's fuller personhood.

Only a small selection of practitioners would be expected to have the necessary specialization to provide 'intensive therapy', but others would have the role of suggesting this and referring as appropriate. There will, of course, be legitimate reasons why some practitioners may decide that enabling sexuality and sexual expression is beyond their scope at present, either in general or in specific client situations. This would include those who may potentially feel that they must abstain as a matter of conscience – such as an interpretation of the Torah by someone of Orthodox Jewish faith which may dictate, for that individual, that homosexuality is a sin, or the strong belief among many Catholics that sexual activity outside marriage is not to be condoned. However, it must be remembered that in many jurisdictions there would be an expectation of an effective referral to a willing practitioner where the client is pursuing something within the realm of the law and regulated scope of practice.

There will be some situations where a client is incapable of consenting to mutual sexual activities. For others, solo sexual activity may manifest in socially inappropriate contexts and attempts to bring this within the realm of the acceptable may not succeed. Regrettably, the goal may become focussed on minimizing and containing these behaviours and enabling others.

No conceptual model of practice will substitute for actual experience of the practice itself. However, this hybrid model has been positively evaluated by practitioners as a useful tool to bolster perceptions of competence and comfort in addressing matters of sexuality and sexual expression with clients [65].

## Supporting Ourselves Conceptually to Support Our Clients

Just as in other matters of participation, engagement, and supported or independent living, there are many benefits that can accrue from the enabling of sexual health and sexual expression. There are also many ways to include non-sexual sensuality in client experience where consenting to sex is not possible. The EPE Model can offer a structured and flexible approach to intervention to help address many sensitive and complex dimensions of rehabilitation practice, including sexuality and sexual expression.

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Aucun à déclarer

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None to declare

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