

# Innovative Approaches to Ethical Issues in the Care of People with Intellectual Disabilities and Potentially Problematic Sexual Behaviours

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## ABSTRACT

This paper reports on ethical issues arising in a clinic devoted to the assessment and treatment of men and women with intellectual disabilities (ID) and potentially problematic sexual behaviors. We argue that ethical principles applicable to the general population are equally applicable to people with ID. Further, we argue that respect for the principles of "autonomy," "non-maleficence," "beneficence," "justice" and "honesty" synergistically improve clinical care. We also suggest that these principles are more important in populations who are labeled with stigmatizing diagnoses such as "intellectual disability" or "paraphilia."

**Key Words:** paraphilia; ethics; consent; intellectual disability; counterfeit deviance

## Introduction

Human rights cannot be granted to some people and denied to others without ensuring that eventually they will be denied to all (McGowan, 2009, p. 86)

Human rights are based on three pillars. The first is that rights are recognized. The second is that they are upheld. The third is that they are upheld by everyone for everyone (Ward, 2007; Rooke, 2003). People with intellectual disabilities (ID) have a long history of being left out or discriminated against on all three fronts (Ward & Stewart, 2008; Griffiths, Owen et al., 2003). The situation is worse in the area of sexual rights and desperate when it comes to consideration of the rights of people with ID who present

with problematic, unconventional or illegal sexual interests and behaviours (Watson et al., 2011 and 2002).

In this paper issues arising from the management of problematic sexual issues in adults with ID will be compared with issues arising from adults without ID. The comments and observations in this paper evolve from data collected in three clinics in Ontario.

## The Clinics and Data Sources

The collaboration resulting in establishment of the clinics described in this paper began in 1994. The context at that time was a typical "top-down" medical hierarchical structure based on a university hospital paradigm. Specifically, hospital resources were organized to provide tertiary care to individuals assessed, treated and referred by physicians in the community.

Once a month, staff at a single community agency would select one or two people identified as most in need of emergency treatment. The number selected was limited by staff resources because the selected people had to be driven to the hospital. This was one of several significant rate-limiting steps.

Because they were selected on the basis of emergent need, they typically required extra staff to ensure safety. Sometimes one referral had to wait for a later appointment because of "incompatibility" issues (meaning they could not tolerate the four hour round trip drive to the hospital with another resident).

Upon arrival at the hospital, they were processed through the routine hospital intake procedure, then seen by a psychiatrist who attempted to assess and treat based on the limited information

available. A significant piece of the available information was always the mental status examination, consisting of an immediate assessment of the referred person. A major problem with this method was that some referred people did not tolerate the road trip well. Sometimes the staff were unfamiliar with the person. Problematically, the person was being assessed far from the environment in which the problems had occurred.

One day, the question arose about whether or not this was the most efficient or effective way to serve the needs of the interested parties. What would happen if the “system” was turned on its head? Instead of reacting to “incidents” by transporting the referred person away from where the events occurred, what if the doctor left the hospital and went to the agency?

Almost twenty years ago we decided to find out. We organized two clinics in southern Ontario that were open to any agency, referring physician, or other person who had concerns about the sexual interests of men and women with ID in their care. The only “catch” was that we requested staff accompany the referral and they were asked to complete a questionnaire suitable for ethically approved clinical research.

The rate of people being referred increased. Satisfaction with the service increased. We published a book (Griffiths, Richards et al., 2002). Most importantly, we have not had any known “hands-on”

(in person physical contact) sexual re-offences committed by anyone under our direct care since then. The range of ethical issues arising is vast. We have attempted to summarize them in Table 1. When reviewing the Table, it is important to remember that the over-all risk of sexual re-offense in the community has also dropped.

In 1975, the World Health Organization (WHO) issued the radical statement that sexuality is an integral part of being human. Given that humans reproduce sexually, the WHO statement appears irrefutable. However, the sexual rights of humans with ID are often treated differently. This statement is doubly true for people with ID who have an alternative sexual orientation (e.g., homosexuality), gender identity (e.g. transsexuals), non-criminal paraphilic sexual interest (e.g., transvestites) or paraphilic disorders centering on criminal sexual interests (e.g., pedophilia).

The practice of protected autonomy in sexual interest and acts was echoed in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) that supported a global commitment to ensure the sexual rights of all people with disabilities, including those with ID. Unfortunately, people with ID who sexually offend or demonstrate problematic sexual behaviour are dually stigmatized due to prejudice against ID, and the unfounded belief that sex offenders cannot be rehabilitated (Fedoroff & Richards, 2010; Henson, 2008; Wilcox, 2004; Johnston, 2002).

**TABLE 1**

Stage of Management	Without Intellectual Disability	With Intellectual Disability	Ethical Issues
<b>Detection of concerns</b>			
Self-disclosed	rare	frequent	self-actualization versus self incrimination
Diagnosed by mental health	rare	occasional	paternalism
Charged by police/ convicted by court	routine	less frequent	societal versus individual rights
<b>Assessment</b>			
Fitness to consent and NCR	assumed	variable	mens rea versus mens actus
Interviews	routine	routine	legal versus medical
Questionnaires	routine	require assistance	standardization and generalizability
Lab tests	routine	variable	consent
Phallometrics	routine	requires standardization	reflects fitness and generalization issues
<b>Treatment Options</b>			
Behavioural	less frequent	routine	paternalism
Individual/group/couple	routine	variable	autonomy
Pharmacologic	routine	routine	special issues
<b>Dispositions</b>			
Not guilty	occasional	more frequent	paternalism versus autonomy
Unfit to stand trial/NCR	rare	occasional	paternalism versus autonomy
Conditional	variable	variable	paternalism versus autonomy
Custodial	increasing	increasing	incapacitation versus rehabilitation
Probation and parole	decreasing	decreasing	incapacitation versus rehabilitation
Sex offender registry	increasing	increasing	criminalization versus medicalization

The criminal corrections and rehabilitation system has an obligation to ensure community safety from all crimes, including sex crime. The primary responsibility of care-providers and clinicians is to treat the offender's mental illness while supporting and guarding the person's human rights and well being (Fedoroff & Richards, 2010). The mandates of Corrections and mental health programs are sometimes presented as at odds. Corrections facilities are mandated to protect the public, while mental health facilities typically provide care focused on the individual. However, to the extent that treatment of people with ID is successful in reducing risk of re-offense, the work of Corrections and mental health can more accurately be regarded as not only compatible but also highly synergistic.

## Problematic Sexual Behaviour and the Ethical Issues

The course of events specific to people with ID is often set in motion before any offense has occurred. A person with ID who is homosexual (gay or lesbian) may be considered dangerous, especially if she lives in a sex segregated facility with other women. A man with ID who has a sexual fetish for shoes may be labeled by staff as a "sexual predator." Remarkably, the process of labeling and discrimination may influence staff and peer suspicion that a sexual offense has occurred, regardless of whether or not formal criminal charges have been laid or whether there is a foundation for police involvement. Often the police are not even called. We think this is a mistake since it places the agency and staff in the role of detectives or judges, which raises conflict in terms of ethical roles. Here we think the adage that "good fences make good neighbors" is applicable. If there is an allegation about a person with ID committing a criminal sexual offense, the police should be called. The best advocacy and assistance are to help the person to get a lawyer and this can be done in a therapeutic manner so the person understands that staff want to minimize harm to everyone. If staff adopt the role of investigating a crime, it confuses roles and can raise professional and ethical concerns that could have been avoided by avoiding a role change. If there are obligations for staff to review incidents before reporting them to third-party authorities, these obligations should be disclosed before the investigation begins and the person should be assisted to obtain independent legal advice.

There is also the risk that the person who has been labeled as "deviant" may subsequently be subject to staff interventions including curtailed freedom. It is not unusual for an individual to essentially "serve time" (typically with strict conditions that restrict their liberties) within the setting that they reside, more often than not under the direction of an agency. This is significant since the criminal justice system in North America is based on the premise that people are presumed innocent and that no one should have their freedom of liberty curtailed without a fair trial and a finding of guilt.

There are a variety of explanations why agencies devoted to advocacy for the rights of people with ID may appear to discriminate against people in their care who have sexual problems. First, service providers have professional, legal and ethical obligations. There may be concerns about the safety of others in the agency.

The agency may be concerned about liability issues ("one bad apple"). The executive, board of directors and/or staff may fear "bad publicity" that might taint the reputation of the agency if the alleged sexual offense becomes publicized. The agency may also want to guard against any further allegations. Typically and understandably, the agency may in all respects want to protect the individual from further legal proceedings. This makes sense since the agency itself needs to be lawful. However, a person accused or suspected of committing a sex crime is often deemed guilty in the eyes of the very people who have the responsibility to guard the inherent human rights and dignity of all the people in their agency.

Ward and Connolly (2008) have suggested that the core values of human rights are well-being and freedom for all people, including those who have ID. Lesseliers and Van Hove (2002) point out that people with ID are often the target of prejudices that all too often include human right violations, especially when controversial issues involving sexuality are at the forefront, and even more so in the case of sexual offences. These prejudices result in part from the long-held but unsubstantiated belief that society needs to be protected from so-called "pronounced" sexuality of people with ID.

Wilson, Clegg and Hardy (2008) point out that care-providers and clinicians are expected to work within ethical principles that respect and promote autonomy in a meaningful way through understanding the unique needs of each individual who has an ID. As clinicians, this is of significant importance when the individual with ID encounters discrimination and prejudice due to problematic sexual behaviours.

## Lack of Sexual Knowledge and Education

Psychosocial sexual education, including both formal and informal teaching, is generally non-existent for people with ID. Failure to address this fundamental need can lead to further infringement of human rights. For example, if people do not learn which acts are private and which may be public, the likelihood that they will engage in public sex increases. If they are charged, their freedom will be curtailed and their ability to engage in consensual, lawful sex will become even more impaired. Agencies have an obligation to ensure that the people they care for receive the information they need to make informed choices. Further, they need to create a culture in which people feel free to discuss concerns and disagreements.

According to Gougeon (2009), the current "ignored curriculum of sexuality" promotes "sexual incompetence" which in turn leads to social exclusion and potential legal problems. Sexuality education is often provided in response to suspected problematic sexual behaviour and taught in the form of proscriptions concerning what not to do. A better alternative is to provide comprehensive cognitively and socially appropriate education in a positive and proactive manner. Education should take the form of teaching individuals what they can do in terms of making responsible and autonomous decisions that promote healthy sexual relationships.

Sexual education that respects individuals and individual differences is a universal right (World Health Organization, 1975).

People with ID can benefit as much, if not more from proper education that accommodates their specific learning challenges. Unfortunately people with ID often go through life with inadequate sexual knowledge and limited awareness of their right to enjoy a healthy sexual life (Lesseliers & Van Hove, 2002). Absent or poor sex education results in increased vulnerability to abuse and increased risk of making poor sexual decisions.

## Lack of Privacy

Privacy is a highly valued right in mainstream society, and yet invasion or interference with privacy in the lives of people with ID is often routine. This is especially true for people living in group living (Richards et al., 2011). According to Hingsburger (1993) lack of privacy can lead to “inappropriate” sexual behaviour (e.g., public masturbation) partly because the person has not been taught to discriminate between public and private venues. If their own privacy is not respected it is not surprising they have difficulty understanding laws concerning respect for the privacy of others. Hamilton (2009) points out that denying a right to privacy is also denying a right to autonomy.

People with ID who are supported by agencies can present with apparent sex related problems that turn out to be secondary to institutional problems. For example agencies that promote or do not curtail flirting between staff often have trouble when clients flirt with staff. Agencies that allow staff to enter client's bedrooms or bathrooms without knocking are more likely to have “voyeuristic” clients (i.e., people who appear to spy on others for sexual purposes). Agencies that permit or encourage staff to hug or kiss clients are more likely to have clients with “frotteurism” (i.e., people who rub against others without consent and for sexual purposes). Agencies in which clients have been sexually abused either by peers, contractors to the agency, or agency staff may have clients at risk of imitating abusive scenarios they have observed or experienced. According to Ward (2007) the aim of treatment and management programs should be to support living as normal a life as possible by accommodating for imposed living arrangements such as the inevitable loss or privacy in group homes.

If a person has a history of public masturbation, in addition to clearly explaining agency policies and societal laws in terms the person can understand, there need to be arrangements to ensure the person also has access to a time and place where she can masturbate in private. After all, the problem is not due to masturbation. The problem is due to doing it in public. People accused of sex crimes often respond better if the problem is framed in terms of joining with them to improve their sense of autonomy, in this case by getting a lock for their bedroom door and making a rule that staff knock before entering. This approach assists in emphasizing private versus public behaviour, promotes discrimination skills, acknowledges autonomy, and demonstrates respect for the privacy and sexual rights of the person and those of the people with whom they live.

## Policies and Procedures

Care-providers are often uncertain about how to deal with situations involving sexuality, especially if the concern involves interests or acts that are personally offensive to staff (e.g. same sex relationships or pornography), problematic (e.g., public sexual conversations), or even illegal (e.g. non-consensual touching). If concerns arise, care providers should consult their professional organization and, if necessary, their own malpractice lawyer. It is important for care-providers to understand their personal legal interests may diverge from the legal interests of the agency they work for and that of the people for whom they care and their alleged victims, each of whom should have the right to obtain their own independent legal advice. According to Wilson, Clegg and Hardy (2008) care-providers fear being held accountable for making incorrect decisions, especially concerning sexual issues. Ironically, the reason staff feel uncomfortable is not due to too much discussion about sex, but rather the opposite, which is lack of staff education about sexuality. Professionals need to be supported and encouraged to raise issues and concerns about the many ethical problems arising from sexual issues and the need to respect sexual autonomy and self-determination, especially in vulnerable populations like those with ID. Agency policy manuals can be helpful but the purpose of sexual policies and procedures is to provide a road map for care-providers consistent with the agency's mission in terms of beliefs, principles, and programs that are offered for people (Griffiths, Owen et al., 2002). Establishment of consistent agency policies is important but true advocacy for people with ID requires establishment of a culture within the agency that champions respect for privacy, autonomy, self-determination, diversity, and communication in ways that are intelligible to all parties.

Richards et al. (2009) point out that clear policies should establish a framework that respects and protects the rights of everyone affected by the policy. Policies concerning sexuality and sexual behaviors should not simply restrict or punish. Moreover, these policies and procedures should be a guide for care-providers to enhance the integrity and autonomy of the individual by explicitly addressing potential ethical dilemmas (Garrett, 2006). For example, a policy against clients talking about sex with staff will not make sense when staff introduce a compulsory sex education group. Providing condoms in a group home that forbids sexual relations is mixing messages. McConkey and Ryan (2001) recommend establishment of rights based sexual policies and procedures. They argue that sex policies based on rights are more likely to be consistent and understandable than ones based on unique situations.

Gilmore and Chambers (2010) found that explicitly written sexual policies and procedures are rare in disability services and that without an agency directed policy care-providers' personal attitudes and beliefs will influence how they respond to sexual situations and questions. As an example, they found that both direct and indirect support staff believed that women who have an ID should be offered less sexual freedom than those who did not have a disability. This survey suggests that women with ID may be subjected to negative reactions by care-providers when they want to have sexual activity of any type.

Swango-Wilson (2008) found that care-providers indicated that the development of healthy sexual identity was based on opportunity

to engage in a variety of relationship experiences. However, care-providers for people with ID are often uncomfortable and therefore unlikely to support social situations that might lead to the development of a sexual relationship. Sexuality policies and procedures that define staff roles and obligations are needed to facilitate the establishment of healthy relationships of all types, including sexual ones. In addition, the policies need to positively encourage staff to be careful that their own personal sexual values and beliefs do not interfere with the development of the healthy sexual rights, values, beliefs, and activities of the people they have been hired to help and support. A staff person who personally does not condone homosexuality should not be allowed to condemn a gay relationship. Further, the same staff person should be expected to assist as much in facilitating a gay relationship as they would a heterosexual one. This is not always easy which is why open communication about concerns, consultation with experts, and review of the literature is so important.

## Assessment

Assessment of problematic sexual behaviors involves more than simply assigning a diagnosis or label. It is ethically important to be aware of stigma associated with paraphilic diagnoses (Fedoroff, 2011). There is a difference between receiving a diagnosis of “adjustment disorder” and “pedophilia”. Watson et al. (2011) argues that successful therapeutic interventions for problematic sexual behaviours require a clear understanding of the problems, etiology, natural course and response to various interventions. Another important issue is why the problems presented at this time and in the current context. Other important issues include whether the incident was incidental or persistent, history of how the problematic behaviour developed, arrest history, number of victims, and so on. There should be careful consideration of whether or not the issues are truly sexually motivated (Johnston, 2002) or whether they represent a form of counterfeit deviance, a term coined by Hingsburger, Griffiths and Quinsey (1991).

People with paraphilic disorders are by definition adult and sexually interested in situations in which there is harm to self or others. Others have suggested the crucial issue is a persistent interest in some type of non-consensual sexual activities (Fedoroff, 2011 and 2009). In contrast, “counterfeit deviance” is defined as a sexual behaviour that appears problematic but which is motivated by a non-paraphilic and sometimes non-sexual interest. For example, a person with ID may expose himself to others because he lived in a home in which public nudity was tolerated, or simply because he does not have a bathrobe.

In our clinics we use a package of assessment instruments that includes a sexual history questionnaire filled out by the individual and their care-provider, the Social Sexual Knowledge and Attitudes Assessment Tool – Revised (Griffiths & Lunsky, 2003), past psychiatric or psychological assessments, court disclosures, and medical history (including medications). Typically phallometric testing is arranged in order to establish a baseline but not as a measure of truthfulness or guilt (Fedoroff, Kuban & Bradford, 2009). Occasionally psychological testing and/or neuropsychological testing is valuable. Our practice is to always review the materials and our opinions and recommendations with

the person as well as all the people he or she wants involved in the assessment. We think this policy is therapeutic and reinforces the ethical principle of respecting the person's autonomy and right to make informed voluntary decisions.

## Disposition(s)

When sex crimes are reported to the police it is often after both the victim and agency responsible for the alleged offender have decided there is an obligation to report. Many problematic sexual behaviours are unreported, especially the first time. Investigating police officers may state that allegations involving people with ID are a lot of work with less than usual likelihood of an arrest leading to a conviction. This is because of the unsubstantiated view that people with ID are poor witnesses and have a tendency to “make things up”.

The courts are not allowed to proceed with a trial if there is a concern that the accused is unfit to stand trial. The main criterion for determination of fitness is whether the accused is able to assist his lawyer in his own defense (Fedoroff, Fedoroff & Peever, 2002; R v. Taylor, 1992). In Canada, if there is a finding of unfitness, the trial stops until the person regains fitness. If the person is unfit due to a permanent condition (such as severe intellectual disability) the person is trapped in a situation in which they do not have the opportunity to be tried. The ethical issues arising from keeping a person under arrest without the opportunity to answer the charges or enter a plea of guilty or not guilty again raise concerns about deprivation of liberty.

A second issue involves whether or not the person merits a defense of being found “not criminally responsible” (NCR). Criteria for this designation are the same across Canada with the exception of Quebec. In addition, each province has its own Review Board with responsibility for disposition of the accused. Section 16 criteria of the Criminal Code require a finding by the court that the person was unable to understand the nature or consequences of his actions at the time of the crime, due to a mental illness. In the event that the trial proceeds and the accused is found guilty, judges are faced with the ethical dilemma of how much weight, if any, should be placed on ID as a mitigating factor. Unfortunately, even though people with ID are over-represented in jails (Griffiths, 2002), few custodial facilities are designed to offer appropriate treatment for sex offenders with ID. Without the prospect of treatment, incarceration of sex offenders with ID represents punishment without rehabilitation.

In contrast, conditional sentences can provide agencies with the authority to impose restrictions on behaviors (e.g., drinking alcohol or going to day care centers) while also providing the chance to work on a safe reintegration into society. A recent Criminal Justice system innovation is the imposition of “sex offender registries.” In Canada, access to these registries is restricted to personnel who have a legitimate interest in knowing whether an individual has a previous sex offense. In the United States, many sex offender registries are publicly accessible, again raising concerns about privacy (Murphy, Fedoroff & Martineau, 2009).

Many dispositions include a requirement that the offender seek treatment. This requirement often has the opposite effect since

it causes the offender to think the requirement to seek treatment is externally imposed rather than encouraging them to take personal responsibility for their offenses. Having said this, it is not infrequent for offenders (with or without ID) to initially oppose treatment but then change their stance when they discover how effective treatment can be not only in curtailing illegal behaviors but also in improving their lives (Fedoroff, 2008).

## Treatment

Ward (2007) states that there should be two core therapeutic goals when considering a strategy for those who sexually offend, namely the promotion of human good and the reduction of risk. A key principle is continuing involvement of the patient and the trusted adult people in that person's life (Fedoroff & Richards, 2010)

Accessibility to effective and comprehensive treatment for individuals with ID who have problematic sexual behaviour has been challenging, mostly due to the limited availability of resources in this specialized area. In addition, there are often discriminatory attitudes against sex offenders with ID who frequently are conserved less amenable to treatment than offenders without ID (Henson, 2008).

Historically, behavioural programs consisting of contingent and aversive consequences and even punishment have been the mainstay of well meaning treatment programs for individuals who have displayed inappropriate sexual behaviour (Gardner, Griffiths & Whalen, 2002). More modern treatments emphasize development of pro-social relationships, as well as interventions to enhance overall quality of life and growth (Steptoe et al., 2006). They found that by helping individuals to develop an attachment to society, they achieve significant personal understanding why they need to obey laws.

Our clinic uses a similar approach. In the initial stages there is a higher degree of caution exercised that typically includes parameters such as supervision, with an eventual goal of independence in the community. These provide opportunities for the individual to build trust by demonstrating successes, while also allowing care-providers to use observation to determine if there are any changes needed in regards to clarifying boundaries and promotion of discussions about healthy versus pathological versus criminal behaviours. We have learned it is important to be accessible to those who are on the front line as new issues arise and questions arise about old ones.

Treatment is best formulated as a response to problems identified by the person receiving the treatment. It is the person with the intellectual disability who has the problem, not the agency or his care providers. Using the ethical principles summarized in Table 1, treatment interventions should be regarded as experiments that are ethically approved by the patient who maintains the right to withdraw consent. Formulated this way, therapists, staff, families and significant others are less likely to lose sight of the goal which is to enhance the person's life with as few adverse side effects as possible (Matich-Maroney, Boyle & Crocker, 2005; Griffiths & Fedoroff, 2009).

It is estimated that 30 to 50% of medications prescribed for individuals with ID are psychotropics, but psychotic disorders are seen in only 3% of people with ID (Tsiouris, 2010). In our clinics, (Fedoroff & Richards, 2010) we have found that many new referrals arrive on "medication cocktails" consisting of many medications from the same class or prescribed to counteract the side-effects of other medications. Treatment often begins with an attempt to determine the rationale, efficacy, and level of understanding that the individual with ID or their care-providers have about the prescribed medication. This process assists in convincing the person with ID that their opinions are of paramount importance and that they are the most important part of the team. People with ID, like others, do not take medications reliably if they do not feel the medication's benefits outweigh the side effects.

Psychotropic medications (including anti-androgens) can play an important part in the treatment of problematic sexual behaviours. However, it is important to weigh the ethical issues including the patient's right to information about the proposed medication, delivered in a manner they understand, and information about the risks and benefits of taking the medication as well as the risks and benefits of choosing not to take the medication.

Rather than being a therapeutic hurdle, we have found the process of reviewing and deciding on whether or not to use medications to be a process that helps to build trust. An effective approach is to explain that all medications have unique effects on unique patients. All medications are prescribed on a trial basis with the clear understanding that the medication will be stopped if it is not working as intended. The patient is encouraged to report back on whether or not the "experiment" was a success or not. In our experience, patients with ID like being regarded as authorities on their condition, which of course they are.

Antiandrogen medications are sometimes used to assist in the treatment of problematic sexual behaviours (Fedoroff et al., 1992; Sajith, Morgan & Clarke, 2008; Tsiouris, 2010). The aim of these medications is to reduce sex drive, which can in turn assist in attempts to alter, or control individual sexual urges and interests. Treatment with anti-androgens has become standard practice for sex offenders but there have been ethical concerns about conducting more definitive double blind treatment trials, especially in men with ID (Lindsay, 2002; Smith & Willner, 2004). Other ethical issues that can arise include the question of whether medication is being prescribed to suppress sex drive, or simply in order to reduce risk for the agency. An important question to ask is whether the person with ID has been provided with full disclosure of the treatment plan in terms he understands; the opportunity to say without prejudice whether or not he agrees, and the opportunity to discontinue treatment if he changes his mind.

## Consent to Treatment

A detailed review of legal requirements for consent to treatment varies by province and is beyond the scope of this paper. In cases involving criminal issues, issues involving consent are governed by legal jurisdiction (e.g. Health Care Consent Act, 1996). However, Griffiths, Owen et al. (2002) take the position that each person is presumed capable to consent to treatment (or to refuse it) unless

there is reason to believe otherwise. Consent has been defined as one's ability to make a decision on what they deem as best for themselves in the interest of self-improvement as long as the outcome does not have a negative consequence for others (Cea & Fisher, 2003). In the case of prescriptions for sex offenders, consent to treatment with medication means accepting treatment to assist in not reoffending and therefore not harming others. Determination of consent can be more complex in people with ID who have a higher prevalence of impaired verbal and listening abilities (Watson et al., 2011).

Ames and Samowitz (1995) point out that the process of assisting in the decision-making process is an example of (positive) paternalism in the sense of taking a fiduciary interest in the patient's rights. The criteria for informed voluntary consent are based on knowledge, understanding and voluntariness the ability to withdraw consent. Most adults with ID can satisfy these criteria if they are provided the appropriate quality and quantity of education at their own pace. The information should be tailored to meet the unique needs of the individual as outlined by Watson et al. (2011).

Fedoroff and Richards (2010) contend there is often a false belief that people who sexually offend are unable to change or improve even with treatment. This belief system is seen systemically as well as with individual care-providers. The result of these misconceptions is the imposition of sanctions such as full supervision for unlimited time frames. These interventions are often justified as a way to keep the community safe. In these situations the person often is not included in determination of the level of supervision or is directly over-ruled. This is less satisfactory than situations in which the person is included in the process and is given a chance to show they can be trusted.

Ward and Connolly (2008) argue that the right to well being and freedom applies equally to people who sexually offended and argue they should have the right to participate in their own treatment decisions. In this context, it then becomes the ethical responsibility of the treatment provider(s) to ensure that the person with an ID is provided with sufficient information in a way that is understandable to the person. If a care-provider is asked to be part of the process of assisting the person in deciding between treatment options, it is their responsibility to set aside their personal views and interests in order to independently assist the person to make their own decision (Boxall & Ralph, 2009) even if it means assisting the person to refuse treatment.

It is important that clinicians strike a balance in determining a treatment path that promotes individual rights while advocating for the best possible evidence based care. Factors for consideration include: risks of the proposed treatment; benefits of the proposed treatment; risks and benefits of alternative treatments or no treatment; the proposed length or treatment; and perhaps most importantly, what is the aim of treatment. How do we know if it worked?

## Follow-up

When we re-organized our clinic, one of the biggest changes was a move from "one-off" consults to on-going care. The current

process begins with an assessment leading to a working diagnoses and differential diagnoses which is presented to the patient by the end of the first session. We think it is important to avoid delays because diagnosis delayed is treatment denied. We therefore make a point of telling the new patient and care providers what we think and why before they leave the first meeting. However, we also emphasize that we might be wrong. We explain that our recommendations for further assessment and our initial treatment recommendations are literally experiments. The role of the patient, together with their care providers, substitute decision makers and legal advisors, is to consider our recommendations and try them out.

At the next scheduled session, or earlier if needed, we review how successful the recommendations were and make new ones. By formulating the process as a series of experiments in which the patient is the "researcher", the patient is empowered and encouraged to be an active participant. By admitting we might be wrong, we communicate that disagreement and open discussion is not only encouraged but an essential part of the process. We always tell our patients that they are in charge and the aim of the entire process is to make their lives better. Fortunately, our experience has been that by valuing the ethical principles of respect for autonomy, nonmaleficence (avoiding causing harm), beneficence (working to help) and justice (including honesty about resources and realistic outcomes) (Beauchamp, 1999) people who consult our clinic almost always do get better, often dramatically.

## Conclusion

Ethics is a sub-specialty of philosophy that considers questions of whether or not actions or inactions can be justified, and if so, how. "Intellectual disability" is a psychiatric descriptor whose definition likely will be modified to make the diagnosis independent of IQ ([www.DSM5.org](http://www.DSM5.org)). Paraphilic sexual disorders are diagnoses based on a collection of unconventional interests or behaviors but the proposed DSM5 criteria will make non-consent less important (American Psychiatric Association, in press; Fedoroff, 2011). It is not surprising that managers, clinicians and front line staff have concerns about the sexual rights of people with ID (Griffiths et al., 2002). If they have concerns, imagine how the people affected feel!

In the old days we used to follow treatment guidelines that were standardized on people without ID and hoped for the best. Fortunately, our patients taught us to do better. The key was changing the focus from what the text books say will happen to what actually was happening. We also think a shift in focus from what happened in the past to what is happening currently and what might happen in the future was important.

But those innovations have been tried elsewhere. What really made the difference were three crucial innovations. First, we changed from the stance of reacting to crises to one of actively seeking out potential problems. In other words we moved from tertiary care in a university affiliated hospital toward primary prevention in clinics in the communities where people live. Second, we included everyone who was willing to participate in the assessment and treatment process. It turns out that more information is helpful, especially if it comes from multiple sources

and multiple perspectives. Thirdly, and most importantly, we put the patient in charge of identifying what was and was not working. Our patients do not write their own prescriptions but they do tell us whether our recommendations worked or not. We think our innovations are ethical, respectful, and practical. Our patients seem to think so too.

We also routinely tell new patients that they have come to the right place and that we think we can help and that they will see positive results quickly. We think this statement is ethical because it sets up a self-fulfilling expectation that affects not only the referral but also the staff who often have heard there is no hope. We think there is nothing unethical about optimism and we invite others to share our view that men and women with ID and problematic sexual interests and behaviors can be treated successfully. The only question is which route the person decides to follow to reach the goal of being a healthy and happy member of our shared society.

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