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**Caring for Persons with Intellectual and
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Ethical and Religious Perspectives

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**Sexual Creators and Intellectual and Developmental
Disabilities**

Being Human in Different Ways

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Abstract

The essay addresses the challenge of protecting persons with intellectual and developmental disabilities who wish to express their sexuality but may be vulnerable, while also promoting their autonomy and capacity for self-determination. We briefly discuss various restrictions commonly placed on them and the persistent biases that keep us from seeking to truly understand their experiences. Drawing on principlism, an ethic of care, the duty to care, and the wisdom of Jean Vanier, we discuss an ethical framework for assisting persons with

intellectual and developmental disabilities and their caregivers in making ethically sound decisions.

Keywords: intellectual and developmental disability, sexuality, common barriers, Catholic moral teaching, ethics of care, principlism, duty to care, Jean Vanier

Introduction

[T]he care of the emotional and sexual dimensions of disabled persons deserves special attention. This aspect is often ignored, glossed over and reduced or even dealt with ideologically. Instead, the sexual dimension is a constitutive dimension of the human being as such, created in the image of the God of Love and called from the outset to find fulfillment in the encounter with others and in communion (John Paul II: 5).

Humans are sexual beings.¹ As John Paul II clearly points out in his message quoted above, our sexuality is not merely one part of us but is constitutive of who we are as human. Our sexuality is entwined with desiring and our desire manifests itself in everything we do, including therefore in sexual activity. Indeed, desire is at the root of our wonder, of our endless questioning, exploring, seeking, and discovering. Human desire is not only or even mainly driven by instinct; rather it is animated by the basic human propensity to understand our world and to understand it correctly, as well as to make of ourselves the person we feel “called” to be. Persons with intellectual and developmental disabilities (IDD),² like all humans, are sexual, desiring beings. However, if the sexuality of persons with IDD is ignored or dismissed, not only is the potential flourishing of that person’s life diminished, it can have negative consequences (McSherry and Somerville: 95).

This essay aims to address issues and questions that concern the sexual expression of persons with IDD. A key consideration, and one that we explore in this essay, is the appropriate balance between promoting participation, independence, and capacity for self-determination of adults with IDD, and protecting them from imprudent lifestyles and health care decisions that may be harmful to them or destructive of community life. The essay is divided into five parts. We first explore the experience of persons with IDD in relation to sexuality and briefly consider five common barriers they and those who care for them currently face. Second, we discuss four types of bias in our understanding of the experiences of persons with IDD that sustain the aforementioned barriers. Next, we review two very different approaches to understanding these experiences, a rationalist and a narrative approach. In part four, we examine whether an ethic of care, when complemented with principlism, offers an effective ethical decision making framework for addressing these challenges. We will conclude that the resulting framework is helpful but also limited. In the fifth part of the essay we suggest that the concept of a “duty to care” can mitigate some of these limitations. We acknowledge in our concluding section that it may only be by adopting

¹ The term “sexual creators” in the essay’s title is drawn from Guindon.

² The authors of this essay are using the term “intellectual and developmental disabilities” (IDD). However, other authors that we refer to use the phrase “intellectual disabilities,” hence the unavoidable inconsistency in terminology.

the kind of faith-based perspective championed by Jean Vanier that we can hope to guide persons with IDD in an ethically sound manner in the expression of their sexuality.

The Experience of Persons with IDD in Relation to Sexuality

As is true of all human beings, persons with IDD want to engage in meaningful sexual activities. Before we critically examine the dialectic between, on the one hand, the desire to protect persons with IDD because of their perceived vulnerability, and, on the other hand, the desire to promote their autonomy and independence, we must be cognizant of the many barriers that block them and that dramatically impact their lived experience. Here, we briefly discuss five of the most serious barriers.

Stigma. While respect for the rights of persons with IDD has grown significantly in the past few decades (Griffiths et al.), stigma persists. As a result, their sexual issues are largely ignored or denied. A significant amount of current research is exploring this problem of neglect or denial. For example, several studies have shown that parents find it more difficult to discuss issues of sexuality with their children with IDD than with their non-disabled children. As a result, persons with IDD living with their families as well as those living in some other form of residence (e.g., group home or specialized group home) are generally not provided with opportunities for sex education (Di Gulio; Griffiths et al.; Kazukauskas; Pownall et al.). Griffiths's team also found that they are often not even allowed to be alone with a friend of the opposite sex.

Myths. In addition to the problem of stigma, myths concerning sexuality surround persons with IDD. They are often viewed as asexual, which results in this important facet of their personhood being ignored or denied. "Advocacy groups and individual authors have expressed concern that persons with disabilities are disenfranchised by a society that inaccurately perceives them as asexual beings and therefore unsuited as romantic partners" (Milligan and Neufeldt: 91). Pope John Paul II highlights this neglect in the statement quoted at the beginning of this essay. Another myth maintains that persons with IDD have "limited social judgment, and therefore, lack the capacity to engage in responsible sexual relationships" (Milligan and Neufeldt: 92). Sadly, this myth has been used not only to bar these persons from all forms of sexuality but also to justify compulsory sterilization. For example, close to 3,000 adults and children were involuntarily sterilized under the Sexual Sterilization Act of Alberta between 1928, when it was enacted, and 1972, when the Act was repealed. Similar sterilization acts existed in British Columbia and Ontario (Puplamu; Christian).

Sexual Abuse. There are higher than average incidents of sexual abuse among persons with IDD. Evidence reveals that persons with IDD are more vulnerable to sexual aggression than non-disabled persons. An important component of the problem is the difficulty of negotiating the balance between "empowering people [with intellectual disabilities] to claim their sexual rights and protecting them from abuse" (Murphy and O'Callaghan: 1347). Studies show that adults with IDD revealed confused differentiation between consenting and non-consenting situations and often did not identify an abusive situation as such (Murphy and O'Callaghan: 1355; Carmody).

Contraception and Sterilization. Although sterilization was raised in relation to the second point above dealing with myths, it needs to be highlighted again in relation to contraception. While the kind of systematic sterilization programs of the past do not exist to the same extent today, issues around sterilization continue to be raised in conjunction with contraception. Three issues in particular are important in relation to our discussion. First, in order to prevent persons with IDD from conceiving children, they are put on some form of contraception or are sterilized. Second, persons with IDD, particularly women, are placed on contraception or are sterilized precisely because they are at risk of being sexually abused. Third, while the short-term solution to sexual involvement and sexual abuse of persons with IDD is the use of contraception and/or sterilization, social pressure to be free of the burden of caring for those with IDD continues to be an underlying current (Kliewer and Drake).

Contemporary Emphasis on Rights. Operating from the foundation of a rights-based approach, the United Nations' *Convention on the Rights of Persons with Disabilities* (CRPD) sets out "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (Article 1). The CRPD emphasizes the importance of recognizing "individual autonomy and independence, including the freedom to make their own choices" for persons with disabilities (Preamble n). In relation to promoting health and well being, the CRPD includes "the area of sexual and reproductive health" (Article 25.a). The rights-based approach is also emphasized in much contemporary literature related to persons with IDD (Griffiths and Owen). However, the claim that persons with IDD have a right to freedom of sexual expression has limits. It is also necessary to consider the legal and moral responsibility of caregivers to prevent sexual activity deemed inappropriate and unsafe. The key difficulty faced by caregivers, already highlighted above in the section on sexual abuse, is the "tension between the growing recognition of a right to freedom of sexual expressions and the need to prevent potentially exploitative sexual activity . . ." (McSherry and Somerville: 92). Rights carry with them responsibilities, which people with IDD might not be capable of exercising and, hence, the need for those responsibilities to be shared/carried out by others as in the duty to care.

The Impact of Bias on the Interpretation of the Experiences of Persons with IDD

The fifth barrier, the emphasis on rights, makes very clear what is actually true of all of the barriers: they do not arise out of sheer malevolence towards persons with IDD. Rather, what sustain these barriers are deep-seated biases. Lonergan argues that there are at least four types of biases that frustrate genuine understanding, and it would seem that all four types apply to society's thinking about persons with IDD and, specifically, their sexuality.

The first type of bias, which Lonergan calls *dramatic bias*, is not a character trait but rather a "block or distortion of intellectual development" (1990: 231) that excludes or represses not only insights but also further questions which these insights might have generated. Markwell further explains that the person "affected by this bias is often capable of brushing aside unwanted insights by labeling them as irrational, or having no basis in fact, in order to avoid facing something that is undesirable" (174). In relation to our topic, dramatic bias can easily reinforce the myth that persons with IDD are asexual; many of the potentially

sexual situations are so troubling that we find ways to avoid the issues. Dramatic bias points to avoidance, which is often completely unconscious.

Egoistic bias prevents the asking of further questions that might shed light on a situation. For example, are we jumping too quickly to the judgment that someone with IDD is incapable of an intimate relationship? Are we refusing to ask further questions that might change our mind? Are we imposing categories that direct thinking one way rather than another? Without realizing it, we may be shaping judgments and decisions in such a manner that they promote our own good and not the good of persons with IDD. Conversely, we may focus only on the needs or rights of an individual with IDD without even considering family, community, and religious values, thereby limiting knowing to the language and perspective of individual rights. Egoistic bias characterizes the subject who is indifferent to his or her community, and intersubjective feeling supports *group bias*. “While it is part of the human condition to desire to exist in unity with others in a relationship of love and support, the problem arises when a group can no longer see beyond its own self-interest to the good of society, and to its place within that society” (Markwell: 180). In this instance a group’s limited horizons displace the broader good of society. This bias has the potential to lead toward attempts at normalizing people with disabilities so as to be free of the burden of caring for those with IDD.

Lonergan refers to the final type of bias as *general bias* or the *bias of common sense*. This is because “it involves the tendency to settle for short-term, ‘quick fix’ solutions to even the most complex problems” (Markwell: 182). Similar to the forms of bias identified above, general bias points to the fact that people are often unable to cope with the world’s problems. There is tension between our human status as physiological beings and our capacity as intelligent actors in the world. We see evidence of this bias in world leaders placing priority on the immediate (job growth or the growth of the economy) while refusing to take into account long-term consequences (sustainability). General bias prevents individuals and communities from choosing what is truly valuable and keeps them choosing only what appears as immediately satisfying (Lonergan 1992). Such quick fix solutions can result in responding to the needs of people with IDD by putting a person on some form of contraception or having him or her sterilized to prevent procreation, particularly if he or she is at risk of being sexually abused. Jean Vanier, founder of L’Arche, highlights a problem in the statement quoted below that is a good example of general bias:

I am moved by the pain of so many parents who are obliged to put their children in centres which encourage sexual activity as a liberation, and which lack a vision of faith and of what it means to be a human being that would give the unifying and inspirational force necessary for true community life.
(187)

The types of bias identified above deepen our understanding of the blocks or barriers that get in our way when reflecting on and addressing challenges around persons with IDD who desire to express their sexuality. In deepening our understanding, it is also important to consider different approaches or methods that influence our thinking on the topic.

Two Approaches to Understanding the Experience of Persons with IDD in Relation to Sexuality

Explicit in the final barrier mentioned earlier, but shaping all five, is a tension between rights and responsibility. This tension not only drives practices towards persons with IDD but also our ethical theorizing. At the risk of oversimplification, we can roughly distinguish two types of theory formation, one that is rationalistic and one that is narrative.

For a rationalistically oriented scholar, particularly one operating in the Catholic moral tradition, sexuality is intrinsically linked to marriage and, in turn, marriage presumes consent. The question arises whether persons with IDD can consent to a sexual relationship and marriage, with the necessary understanding and appreciation of its meaning. Each potential marital partner must be able to consent to, and therefore grasp the meaning of, the vows he or she is making. It is this consent that lifts human sexuality from the level of mere instinct or from potential abuse on the part of one of the participants. We human beings are not merely creatures driven by instinct; we are also creators in the sense that we seek to live meaningfully. Our actions are not arbitrary or merely instinctual and our actions participate in and create meaning. A meal together is more than satisfying hunger. Cultures from around the world participate in more or less elaborate rituals around meals, rendering them a *human* activity proper. Sexuality is also more than instinct. It becomes human in the rituals, the commitment, and the meaning we create in our relationship with the other. Hence, the importance of consent is central.

Flannery suggests that marriage for those who are intellectually disabled would be a pretense: “To perform a wedding ceremony between two mentally handicapped persons would be to perform a charade. There would be nothing there – no marriage – since marriage presumes ability to consent to a partnership of the whole of life” (24). Flannery, coming from the Roman Catholic tradition, asserts that a “proper understanding of marriage generally will help us understand the issue of sexuality among the mentally handicapped . . .” For Flannery, following Aristotle and Aquinas, our sexuality cannot be separated from our rationality. He says that marriage, in this earthly life anyway,

is a cultural and legal *entity* with a particular nature, possessed of proper characteristics, such as the requirement that it be between one man and one woman, who are capable of understanding what they are doing when they contract to enter into a marriage (15).

Marriage, and consequently human sexuality in general, understood in this light, is “human nature’s way of ordering its sexual life” (Flannery: 17). Whatever act a person performs, whether of a sexual nature or something else, must fit into the rational order that humans are capable of understanding and living. As a “practical rationality,” marriage aims not at “truths” so much as at “goods.” The traditional goods of marriage identified in Flannery’s article are the generation and education of offspring, mutual fidelity between spouses, and the sacramentality of the marriage meaning spouses are inseparable (22). In this light, it seems hard if not impossible to imagine how persons with IDD would meet the criteria of proper human sexuality ordered toward rationality.

An alternative to Flannery's rationalist approach to the question of sexual activity of persons with IDD is the work of Hauerwas, who is inspired by Stump, on narrative or stories. Hauerwas rejects attempts at lifting up the disabled to a standard such as rationality when considering how to be with a person who is disabled. Instead, Hauerwas suggests we need to remember our own vulnerability. If we learn how to be with our own disability we may truly learn how to be with those whom we call intellectually disabled. Hauerwas acknowledges the wisdom of Jean Vanier who asserts that our moments of vulnerability make, "the work of the Holy Spirit possible." "To be young or old is to lack the means, as the disabled do, to disguise our desire to be loved" (Hauerwas: 2).

Here, the focus is not on rationality but on love, which asks the person who is disabled, what is your story? For Vanier and Hauerwas, listening to the story of a person with IDD is to truly encounter him or her as a person rather than a category like "disability." Moral deliberation is truly ethical when it draws from encounter rather than categories. Stories told to us by others and, in this case, by a person who is intellectually or developmentally disabled, "identify different kinds of suffering and raise different kinds of questions and beg for different kinds of responses" (Hauerwas: 4). If we are willing to listen to the stories of persons with IDD, we will realize that notwithstanding the vastly different forms these stories may take depending on the IDD, there is a common thread: these persons reach out for love in the same way that all humans do. The desire for sexual intimacy is part of the deep desire and need for love.

What Hauerwas suggests is the need to listen to the desire, to truly hear it and respect it. To acknowledge our own desire and need for love and to communicate it to the person with IDD is to begin to explore concrete possibilities of addressing the sexual challenges of persons with IDD. It is to meet persons in authenticity, face to face rather than from a position of power and authority. It invites the person with IDD to speak his or her own desire and anguish in whatever way is possible.

Two Approaches to Guiding Persons with IDD Expressing Their Sexuality

The radically different approaches to understanding the experiences of persons with IDD sketched above inevitably give rise to very different ways of guiding them. One is characterized by an emphasis on rights and rigid rules; the other inspires and enthuses but offers little in terms of general norms, let alone policies and laws. McSherry and Somerville suggest that an ethics of care, modified with the kind of principlism that has become very common in biomedical ethics, can provide a framework for effective ethical decision making around the sexual activities of persons with IDD. They consider an ethic of care "particularly relevant to the issue in question, because it attempts to find creative solutions to remove or to reduce conflict, rather than simply determining if one person's rights dominate claims on the part of another" (91). Because the basis of an ethic of care is relational, it does not provide clearly delineated directives for addressing concerns of sexual activity among persons with IDD. However, it is possible to identify some basic elements or strategies, which can guide one's deliberations.

First, similar to Hauerwas, an ethic of care gives priority to social relations and connectedness between persons. It offers a broader approach than viewing persons as individuals with rights to be protected (McSherry and Somerville: 93). Hence, moral

deliberation is based on relationship rather than rights and responsibilities. An ethic of care would treat the question of sexuality among those with IDD through a consensual approach.³ Citing Freedman, McSherry and Somerville underscore the need for open communication, shared decision-making and mutual respect (95).

Second, an ethic of care is future oriented rather than past oriented. It is focused on building relationships and preventing conflict. What is important here and underlies the concern of this essay is promoting the fecundity of persons with IDD in a way that enhances human flourishing for the individual and the community. An ethic of care engages this question through its relational orientation and its emphasis on promoting the self-development of persons with IDD.

Third, an ethic of care emphasizes being attentive to the person one encounters in the face-to-face relationship. That person is unique and particular and so requires openness to listen and hear his or her needs and desires rather than impose general rules and prohibitions. Caring for a person with IDD requires that one does not presume to know what this person desires or thinks. Rather, one must ask, what are the needs and desires of this particular person for whom I am caring? What would this person say?

An ethic of care seeks “creative ways to accommodate diverse interests” (McSherry and Somerville: 94), balancing individual and collective interests in order to promote harmony and well being among all. As such, it attempts to move beyond an ethic of rights and rigid rules. However, this strength is also its main weakness. While an ethic of care provides invaluable insight into the importance of concrete life experiences here and now, still we need frameworks to provide more sustained order and balance in our lives. McSherry and Somerville believe a principle-based ethics provides such a balance and discuss ethical decision-making about sexual engagements by persons with IDD in reference to the four familiar principles that are commonly used in health care decision-making.

Autonomy can be defined as the principle of respect for persons and their right to determine their own destiny even if we disagree or think their decision will be potentially harmful to them. The exercise of autonomy is dependent on capacity and decisions can be overridden if the person is determined to be incapable. Short of such incapacity, any form of interference in an intellectually or developmentally disabled person’s right to sexual expression would need to be justified starting from the principle of autonomy. Thus, McSherry and Somerville argue that an intellectually or developmentally disabled person’s autonomy “or even just their decisions concerning themselves with regard to their expression of their sexuality” should be “respected to the greatest possible degree” (97). However, this leaves unanswered what degree is in fact possible. Moreover, a well-known shortcoming of the principle of autonomy is that it only tells us how we ought to respect persons who are capable of exercising their autonomy; it does not tell us how we ought to respect persons who lack that capacity. If we turn this capacity into a necessary condition for consent, and consent a necessary condition for marriage, and marriage a necessary condition

³ In their article, McSherry and Somerville use “institutionalized persons in need of special care.” However, because McSherry and Somerville are not restricting their study to persons with “intellectual disability,” when referring to their article, we will use “persons with IDD.”

for sexuality, we would end up rigidly excluding all persons with IDD from meaningful engagement in sexuality, as Flannery's approach suggests.

Non-maleficence is the second principle and it essentially means that a person must first do no harm. McSherry and Somerville include the prevention of harm under this principle. In relation to sexuality, if the only way to protect a person with IDD or prevent harm to others were to limit his or her sexual expression, according to this principle, the action of limiting might be justified. But such limitation of persons can be considered harm to the persons so limited. Thus, a balancing of harms becomes necessary, which is what the principle of *justice* calls for. The principle of justice, defined as "fair, equitable and appropriate treatment in light of what is due or owed to persons" (Beauchamp and Childress: 250), appears to bring us back to a rights-based approach: a person with IDD has the right to be treated, as far as possible, equally and fairly with respect to his or her sexual expression. Moreover, the principle of justice does not itself tell us what is due or owed to whom.

The principle of *beneficence* goes beyond non-maleficence in that it does not merely place limits on potential harms, but actually requires the promotion of the other's welfare and well-being. Rather than merely preventing harm, the principle of beneficence invites us to promote positive expression of an intellectually disabled person's sexuality. In this regard, the basic sexual drive of human beings can be expressed in ways broader and richer than only genital sexuality. Sexual expression does not necessarily mean genital sex; sexuality as a *human* activity proper involves meaningful and meaning generating sexual engagement. A person's sexuality can be expressed in other life-giving ways if a sexually intimate relationship of a genital nature with another person is considered too harmful either at the particular time or on a longer-term basis. Unfortunately, the principle of beneficence only confirms that we must be concerned with the good of all persons involved; it does not tell us what those goods are and how they shall be realized.

The admittedly overly succinct description and application of the four major principles nevertheless makes clear that they are insufficient as a basis for addressing the ethical challenges at hand. A principle-based approach provides a necessary beginning to attain the kind of generally binding norms and maxims that an ethics of care cannot deliver, but principles alone cannot provide direction on these issues.

The Duty to Care

In the previous sections, we have argued that the experiences of persons with IDD who seek to express their sexuality is marred by a multitude of barriers, some of which are truly invasive and coercive, but all of which are restrictive. We have pointed out that these barriers are sustained by widespread and persistent biases that keep us from seeking to truly understand and appreciate the lives and experiences of persons with IDD. These biases also impact our ethical theory development. Many ethical reflections, not least within Catholic moral doctrine, are characterized by a high degree of rationalism, which tends to lead to restrictive policies. In an attempt to provide correction, theologians such as the protestant ethicist Hauerwas and the Catholic founder of the L'Arche movement, Jean Vanier, have emphasized the importance of meeting persons with IDD in their world and listening to their stories. An ethic of care, as advocated by McSherry and Somerville, resonates with the latter epistemology, but they readily acknowledge, it fails as a framework for general ethical

decision-making and policy development. They propose to adopt the principles that have been successfully employed in biomedical ethics. Upon closer inspection, the same problems that plague bioethical principlism also surface here and the resulting ethical theory remains lacking. Without pretending to have a completely adequate resolution for this quandary, which is most complex indeed, we propose that the concept of the duty of care may be helpful (drawing upon the work of Godkin and Markwell).

The “duty to care” is a concept that is used by many healthcare professions in laying out their obligation toward those for whom they care. It is often utilized in public health emergencies because of the conflicts among competing duties and the need for a framework in thinking through competing claims. As we have emphasized several times in this essay, caring for individuals with IDD likewise requires a balance between rights, responsibilities, and competing goods. In issues concerning sexuality and persons with IDD there is a need to understand underlying values and possible conflicts in order to reach an ethically justifiable conclusion or policy. Hence, we believe it may be efficacious to adopt the duty to care as a tool for thinking through some of the claims made by persons with IDD as they struggle with their desire for sexual expression. The duty to care for persons living with IDD draws to the forefront several ethical values that might be compromised, overemphasized and/or come into conflict.

We presume that individuals, families and groups have a duty to care for people with IDD. In that most basic sense, this duty is generally acknowledged and not very controversial, but it is not especially helpful in sorting through some of the conflicts discussed earlier. However, if we dig deeper and examine the specific values that flow from this basic duty, a clearer picture emerges. Borrowing from Singer et al., we distinguish six such values.

The first is *reciprocity*. Neither individuals, families, nor groups should carry this responsibility alone. There is a reciprocal responsibility operative here that calls for collaboration and support. The second value is *individual liberty*. Care should be taken in restricting anyone’s liberty and these restrictions should be legitimate and necessary. The least restrictive option should always be chosen. The third value is *protection from stigmatization*. As mentioned previously, persons with IDD are at risk of being stigmatized. Any action taken in order to carry out the duty to care ought to recognize the potential for stigmatization. Fourth, *protection of the public from harm* is part of our duty to care. The fifth value refers to *transparency*. There is a duty to protect the public from harm. People living with IDD have a right to receive information regarding their care even if they are deemed “incapable.” There is also a need for sharing information in order to empower and respect the dignity of the person. The final value is *solidarity*, which does not suggest that group interests supersede individual interests but that communities have a responsibility to assist in carrying out support for those who are unable to support themselves. In the end, solidarity means helping each other achieve a good that none could achieve on his or her own. Persons with IDD not only receive this good, they also contribute to it.

Concluding Reflections

The voices of persons with IDD and of those who care for them must be heard. They must be listened to and not ignored or repressed. In this listening stance, we must come to

recognize that persons with IDD have equal, inherent dignity and are sexual beings or sexual creators similar to non-disabled persons. Their inherent dignity is not contingent on rational capacity. There are other “carriers of meaning” (Loneragan 1990: 81-85) operative in being human that need to be emphasized, equally valued, and recognized as contributing to moral reflection. It is important to recognize that the human body is a carrier of meaning pointing to the whole person. Human beings are relational beings. Human dignity rests in our capacity to be loved and to love. This implicates human sexuality. The fruit of sexuality is more than offspring; it involves how we express ourselves and encounter each other as gendered beings.

Vanier draws both on a theological and philosophical reading of the sexuality of persons with disabilities and affirms that “disturbed sexuality” is related to an “anguished, wounded heart” and “the cry of violence” (3). He moves beyond focusing on genital sexuality and considers sexuality as part of the whole person and challenges a strictly rights based approach. “Some speak of the right to sexual pleasure, but very little of the right to relationships. It is as if genital sexuality was entirely cut off from the person and from life” (6).

As someone who has lived with persons with IDD for 50 years, Vanier has considerable wisdom to share. His approach is grounded in the Christian faith in which he considers “his life in community with the disabled as a sign ‘touching the roots’ of our humanity” (Comensoli: 118). His wisdom comes from a careful balance between principles and care, between theory and practice, both of which, as we have tried to show in this essay, are important in addressing the challenges of sexual expression for persons with IDD. Vanier has dug deeply to consider a holistic approach to healthy sexuality for persons with developmental disabilities, yet never pretends to offer easy solutions to concrete challenges. And neither shall we.

In order to guide someone with a mental handicap, it is not enough to impose prohibitions or to rely simply on dialogue. We must help the person find new energies, a deeper freedom, other centers of attraction and interest. We must discover how to help people, not simply to control their sexual compulsions, but to pacify their genital sexuality at its roots. In other words, we must discover the deep meaning and the richness of that sexuality, but also, its limits and its relativity (Vanier: 8).

Bibliography

Beauchamp, T. L., and J. F. Childress

2013 *Principles of Biomedical Ethics*. Seventh edition. New York: Oxford University Press.

Carmody, M.

1991 “Invisible victims: Sexual assault of people with an Intellectual Disability.” *Journal of Intellectual and Developmental Disability* 17, 2: 229-36.

- Christian, T. J.
1973 *The Mentally Ill and Human Rights in Alberta: A Study of the Alberta Sexual Sterilization Act*. University of Alberta, Faculty of Law.
- Comensoli, P. A.
2011 "Descending the Ladder: The Theological Anthropology of Jean Vanier's Key Metaphor." *Journal of Religion, Disability & Health* 15, 2: 115-29.
- Di Giulio, G.
2003 "Sexuality and People Living with Physical or Developmental Disabilities: Review of Key Issues." *Canadian Journal of Human Sexuality* 12, 1: 53-68.
- Flannery, K. L.
2004 "Marriage, Mental Handicap, and Sexuality." *Studies in Christian Ethics* 17, 11: 11-26.
- Freedman, A.
1993 "The Physician-Patient Relationship and the Ethic of Care." *Canadian Medical Association Journal* 148, 6: 1040.
- Godkin, D. and H. Markwell
2003 "The Duty to Care of Healthcare Professionals: Ethical Issues and Guidelines for Policy Development." Submitted to SARS Expert Panel Secretariat.
- Gregson, V.
1988 "The Desire to Know: Intellectual Conversion." *Desires of the Human Heart: An Introduction to the Theology of Bernard Lonergan*. Edited by V. Gregson. Mahway: Paulist.
- Griffiths, D. M., F. Owen, L. Gosse, K. Stoner, C. Y. Tardif, S. Watson, C. Sales, and B. Vyrosko
2003 "Human Rights and Persons with Intellectual Disabilities: An Action-Research Approach for Community-Based Organizational Self-Evaluation." *Journal on Developmental Disability* 10, 2: 25-42.
- Griffiths, D., and F. Owen, editors
2008 *Challenges to the Human Rights People with Intellectual Disabilities*. London: Jessica Kingsley Publishers.
- Guindon, A.
1986 *Sexual Creators*. Washington D.C.: University Press of America
- Hauerwas, S.
2012 "What's Love Look Like: Learning to be with Disability." ABC Religion and Ethics (May 18). Available at: <http://www.abc.net.au/religion/articles/2012/05/18/3505442.htm>
- John Paul II
2004 "Message on the Occasion of the International Symposium on the Dignity and Rights of the Mentally Disabled Person" (issued on January 5). Available

online at http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/january/documents/hf_jp_ii_spe_20040108_handicap-mentale_en.html.

Kazukauskas, K. A.

- 2010 "Disability and Sexuality: Knowledge, Attitudes, and Level of Comfort among Certified Rehabilitation Counselors." *Rehabilitation Counseling Bulletin* 54, 1: 15-25.

Kliewer, C., and S. Drake

- 1998 "Disability, Eugenics and the Current Ideology of Segregation: A modern moral tale." *Disability and Society* 13, 1: 95-111.

Loneragan, B. F.

- 1990 *Method in Theology*. Toronto: University of Toronto Press.
1992 *Insight: A Study of Human Understanding*. Volume 3 of *Collected Works of Bernard Lonergan*. Edited by Frederick E. Crowe and Robert M. Doran. Toronto: University of Toronto Press.

Markwell, H.

- 2005 "The Role of Feelings in Informed Consent: An Application of Bernard Lonergan's Work on Affect and Cognition." Ph.D. Dissertation. Saint Paul University/ University of Ottawa.

McSherry, B., and M. Somerville

- 1998 "Sexual Activity among Institutionalized Persons in Need of Special Care," *Windsor Yearbook of Access Justice* 16: 90-131.

Milligan, M. S., and A. H. Neufeldt.

- 2001 "The Myth of Asexuality: A Survey of Social and Empirical Evidence." *Sexuality and Disability* 19, 2: 91-109.

Murphy, G. H., and A. O'Callaghan

- 2004 "Capacity of adults with Intellectual Disabilities to Consent to Sexual Relationships." *Psychological Medicine* 24, 7: 1347-57.

Pownall, J. D., A. Jahoda, R. Hastings, and L. Kerr

- 2011 "Sexual Understanding and Development of Young People with Intellectual Disabilities: Mothers' Perspectives of Within-Family Context." *American Journal on Intellectual and Developmental Disabilities* 116, 3: 205-19.

Puplamu, K. P.

- 2008 "Knowledge, Power, and Social Policy: John M. MacEachran and Alberta's 1928 Sexual Sterilization Act." *The Alberta Journal of Educational Research* 54, 2: 129-46.

Singer, P., S. R. Benatar, M. Bernstein, A. S. Daar, B. M. Dickens, S. K. MacRae, R. E.

Upshur, L. Wright, and R. Z. Shaul

- 2003 "Ethics and SARS: Lessons from Toronto." *British Medical Journal* 327: 1342-44.

United Nations

2006 *Convention on the Rights of Persons with Disabilities (CRPD)*. Available online at <http://www.un.org/disabilities/convention/conventionfull.shtml>.

Vanier, J.

2008 *Man and Woman He Created Them*. Mahwah: Paulist.