The demands of human dignity: Sexuality in the young person with intellectual disabilities

EARL K. FERNANDES¹ AND ASHLEY K. FERNANDES²

¹*Athenaeum of Ohio/Mount St. Mary's Seminary of the West, Cincinnati, OH, USA*

²*The Ohio State University Center for Bioethics and Medical Humanities, Columbus, OH, USA*

The topic of sexuality among the disabled is often ignored within Catholic seminaries; within pediatrics, it is treated as a “problem” where the best solution is contraception or sterilization. In this article, the authors argue for an approach to sexuality in disabled youth that is grounded in the inherent dignity of the person, borne out of Christ's own humanity. Because sexuality is a part of the human person in his or her totality, it cannot be ignored or obscured; on the other hand, it cannot also be the overriding “problem” which defines them. Rather, by friendship, love, and covenantal solidarity with the disabled person, we can begin to set an example for them and for society that there are goods to be strived for beyond the physical. The demands of dignity require practical changes in seminary and medical education and practice.

Keywords: Disability, Sexuality, Pediatrics, Catholicism, Dignity

INTRODUCTION

“Ashley X,” a child born with idiopathic static encephalopathy in 1997, was non-ambulatory and profoundly mentally disabled, having no chance of speaking, learning, or communicating with her parents and caregivers. In 2004, she began to exhibit secondary sex characteristics, and, in consultation with her physicians, the parents authorized a hysterectomy, appendectomy, high-dose estrogen therapy to achieve growth attenuation, and bilateral breast bud removal—all in Ashley's “best interests.” Controversy over this procedure erupted in 2007—particularly among the disability-rights community—when the details became public; the

parents themselves published an online spirited defense of their decision making (Ashley's Mom and Dad (AMD) 2007; Pillow Angel 2012). In 2009, two endocrinologists and two bioethicists published a defense of the “Ashley treatment” in the journal *Pediatrics* (Allen et al. 2009).

A full critique of that defense and similar arguments (Liao, Savulescu, and Sheehan 2007) is beyond the scope of this paper. We note, however, that one telling justification for the “Ashley treatment” was that a hysterectomy would keep Ashley from having the discomforts of her menstrual period, keep her “safer” from sexual predatory behavior, and ultimately prevent unwanted pregnancy (Pillow Angel 2012). Furthermore, some suggested that

her child-like appearance due to growth attenuation and hormonal treatment would also aid in preventing sexual abuse.

There are obvious but serious errors in such a justification. Hysterectomy would prevent pregnancy, but not sexual abuse—in fact, it might increase its likelihood by making it harder to detect. Likewise, a lack of secondary sex characteristics and bilateral breast bud removal would not necessarily stop unwanted sexual advances, as we know from the pathology of pedophilia. Children with disabilities are thought to suffer sexual abuse at a rate of at least 2.2 times higher than children without disabilities (with some placing the comparative rate even 4–10 times higher (Petersillia 2001)), a statistic of grave concern (Crosse, Kaye, and Ratnofsky 1993).

The mistreatment of persons with intellectual disabilities in their nature as sexual beings has not been limited to the current secularist century, of course.

Oliver Wendell Holmes is thought to be one of the most distinguished justices to serve on the United States Supreme Court, yet in the U.S. Supreme Court case *Buck v. Bell* (1927), he infamously concluded the ruling of the court with the words: “Three generations of imbeciles is enough!” In an 8-1 decision, with the dissenting vote coming from Justice Pierce Butler, a Catholic, the Supreme Court upheld a statute instituting compulsory sterilization of the “unfit,” including those with intellectual disabilities. Carrie Buck, a person with an intellectual disability, who had been a sexual abuse victim, was forcibly sterilized by the state of Virginia (Lombardo 1985). We have previously shown through a historical analysis of Butler’s writings that, although he did not write a specific dissenting opinion, his dissent was almost certainly due to his deeply held Catholic faith and his assent to a moral philosophy rooted in the natural law (Fernandes 2002).

Despite Butler’s lone dissent and some initial outrage over the Ashley case (the demands for the same “treatment” have increased dramatically (Pilkington and McVeigh 2012)), these cases highlight the long-standing plight of persons with intellectual disabilities, particularly in the area of human sexuality. The whole issue of human sexuality in persons with intellectual or other developmental disabilities has largely been ignored by Catholic theologians and by seminaries. *If* such issues are treated, they are dealt with in moral theology and marriage canon law; in these cases, one is either considering the sterilization of persons with such disabilities or considering their capacity for entering into marriage. Largely, the sexual issues of the person with intellectual disabilities are ignored by the Church and by the public (where they are more often than not treated as a “social problem”).

In the field pediatrics, the American Academy of Pediatrics (AAP) has issued guidelines for dealing with the sexuality of persons with disabilities (AAP Committee on Bioethics 1999; Murphy and Elias 2006). The AAP, in fact, acknowledges that human sexuality is a complex and multi-dimensional aspect of the disabled person that requires prudence and caution in keeping with the respect due to all persons. It also places the issue of forced sterilization in its proper historical context within the United States as an abuse of the eugenics movement and an affront to those with disabilities. But at the same time, it also (predictably) assumes that sexual maturity and future procreation are “problems” for the disabled, which can be solved through contraceptive means:

Whenever possible, pediatricians should involve their patients with developmental disabilities in decisions about reproduction and should advocate for the least permanent and intrusive method of

contraception consistent with the lowest risk for the patient. (AAP Committee on Bioethics 1999, 340)

And, of course, the AAP approves of sterilization if the intellectually disabled person desires it, has decision-making capacity, and the parent believes it is in the best interests of the child. Such recommendations should not surprise us. “Respect for persons” which is derivative of autonomy alone does not look for the good of the person in her wholeness—as a creation of God whose dignity is experienced in communion with others. This connection with God brings a further connection to truth into high relief. But this is precisely why the voice of the Church is needed—to inform and reveal these inner truths about man, within its competence, and to thereby enrich and illuminate authentic solutions to complex medical and ethical issues.

In his message to the participants of the international symposium on “The Dignity and Rights of the Mentally Disabled Person,” Pope Saint John Paul II highlighted this neglect of the topic:

In this regard, the 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. The premise for the emotional-sexual education of disabled persons is inherent in the conviction that their need for love is at least as great as anyone else’s. They too need to love and to be loved; they need tenderness, closeness and intimacy. Unfortunately, the fact is that disabled persons find themselves living these legitimate and natural needs in a disadvantaged situation that becomes

more and more obvious as they grow from infancy to adulthood. Despite the damage to the mind and the interpersonal dimension, disabled people seek authentic relationships in which they can find appreciation and recognition as persons. (John Paul II 2005, 5)¹

To this point, collectively, the Church has not dealt substantively with this issue, as witnessed by the paucity of theological literature on the subject and its near-total absence in seminary curricula. Such reflection by the Church is absolutely necessary if change is to come within pediatric medicine through the teaching of Catholic healthcare professionals, and through dialogue with those who differ from us. In some respects, the AAP begins the needed dialogue in the medical field:

Sexual development is a multidimensional process, intimately linked to the basic human needs of being liked and accepted, displaying and receiving affection, feeling valued and attractive, and sharing thoughts and feelings. It not only involves anatomic and physiologic functioning, but it also relates to sexual knowledge, beliefs, attitudes, and values. Sexuality should be considered in a context that extends beyond genital sex to include gender-role socialization, physical maturation and body image, social relationships, and future social aspirations. Like all adolescents, teens with disabilities may express desires and hopes for marriage, children, and normal adult sex lives. (Murphy and Elias 2006)

If the sexual dimension of the person is constitutive of the person and the disabled person’s need for love is as great as any other person’s, then not only *could* the subject be addressed by the Church, it *should* be treated in light of the demands of equal and inherent human dignity.

HUMAN DIGNITY AND CHRISTIAN ANTHROPOLOGY

In the teaching of moral theology and Catholic social teaching, seminary professors repeat the phrase like a mantra: “respect for the dignity of the human person.” If one understands that persons have equal, inherent dignity, then one can see *why* we must treat those with intellectual disabilities as persons, inclusive of the sexual dimension of their persons, granting them the same respect afforded to others.

But what is dignity? Elsewhere, we have reviewed the notion of dignity and defended it in the context of end-of-life decision making (Fernandes 2010). Historically, the word “dignity” has been used in many confusing and contradictory ways. Some philosophers even question the usefulness of the term—calling it “meaningless”—since its derivation is outside of the autonomy rubric (Macklin 2003, 2004; Pinker 2008). Others such as Patrick Lee, Robert George, and Martha Nussbaum have defended the concept (President’s Council on Bioethics 2008; see Lee and George 2008). Edmund Pellegrino contended that contemporary culture tends to favor a concept of dignity known as *attributed* dignity, in which the foundations of dignity depend on “the capacity for ‘meaningful relationships,’ social worth, the quality of life, freedom from disability, satisfaction of aspirations, autonomy, and dozens of other capabilities as judged by humans to be important for human happiness” (Pellegrino 2007). Sometimes *attributed* dignity is called personal dignity. For example, disability or debilitating illness could be seen as robbing a person of his or her dignity. Problems arise when one ascribes the intrinsic value of a person to the perception of a person’s attributed dignity. The disabled person is particularly vulnerable when he or she is seen as having “less

worth” because he or she does not “reason” at the same “high” level as other members of society. A person with intellectual disabilities may be subjected to exploitation and discrimination.

In contrast, another understanding of dignity, which is compatible with Catholic thought, is that of *inherent* dignity, which is sometimes called basic dignity (Pullman 2002). Inherent dignity is a universal, inalienable moral quality, which the person does not earn and which cannot be taken from the person. It is not contingent upon a person’s physical or intellectual abilities. Inherent dignity provides a *prima facie* reason for not exploiting or discriminating against a vulnerable person.

Thomas Aquinas argued that “person” signifies what is most perfect in all nature—that is, a subsistent individual of a rational nature (Aquinas, *Summa Theologiae* I, q. 29, a. 3, co.). However, a person’s experience of dignity is an experience not simply of a “being with a rational capacity” but of the irreplaceable and utter uniqueness of this particular person in his or her complexity. John F. Crosby argues that there is a twofold source of the dignity of persons (Crosby 2001). For Crosby, the dignity of the person arises not only from his or her rational nature but from a person’s “incommunicability.”

Dignity therefore rests not only on what we have in common (for example, reason) but also on what is different about the person, our uniqueness, which is recognized, not in abstraction, but in encounter. Karol Wojtyła’s essay, “On the Dignity of the Human Person” (Wojtyła 1993), describes dignity as a natural greatness discovered by *experiencing* a person; the lived experience of this value is evident both on an individual level and communal level. Each person has a unique set of experiences that make us admire and love that person. A person’s absolute unrepeatability is revealed through free action, through

the encounter with another. It is discovered through love, which reveals and confirms the value of a person who cannot be replaced (Fernandes 2008, 190).

Note that up until now, Catholic physicians could substantially argue for their vision of dignity in the public square as applicable to the disabled person, without ever mentioning the Church. This is of significance, for, a sound philosophical anthropology is the basis from which we derive an authentic moral philosophy. Often disagreements in bioethics are sharp and severe because the views of what the nature of the person truly is are disparate and unreconciled. If inherent dignity can be affirmed for the disabled person through a reflection on their incommunicability—that is, our experience of the disabled person as unique person—their sexuality would not be seen as a “problem”; rather we would view it as a part of their nature, and then only approaches which respect them as whole persons could be pursued.

But there is surely more. As Catholic Christians we do not fall for the “rationalist error”—that all truth can be explained by philosophy alone; instead, we believe that Christian thought could illuminate medicine and science and bring these disciplines to their fulfillment. What does Christianity contribute to the understanding of the person and human dignity? To answer, one must examine the hallmarks of a Christian anthropology, including the Christian understanding of the person as existing in relationship with God; as being made in God’s image; and as a unified totality.

The human person as a creature exists in relationship with God. This relationship is one of dependence but remains dialogical and participatory. From a theological perspective, the person is the “only creature on earth that God has willed for Himself.” This relationship is absolutely

unique and special. The roots of the value and of the inviolability of every human life ultimately exist in God.

Human life has intrinsic value because of this relationship with God. Returning to the concept of inherent dignity, Pellegrino elaborated on the import of Christianity:

The Christian conception of dignity is centered in the unique worth of the human person, created in the image of God, the one species chosen by God for the Incarnation of His only Son. God’s only Son died that man might be redeemed. For this reason, dignity is the source and foundation of human worth ... This inherent God-given dignity is radically different from the dignity we attribute to those we admire or respect because of certain external or acquired capabilities. (Pellegrino 2007, 25)

It is this relationship with God and our inherent God-given dignity that allows Christians to resist overly aggressive “quality of life” arguments and attitudes. Some argue that certain lives do not meet a minimum standard and therefore those lives are not considered to be lives of good quality. Those with intellectual disabilities are often counted among this number and are routinely denied basic rights without an evaluation of the particular person and his or her capacity—including the right to marry (if the disability is not severe), or at the very least, the right to remain whole and be treated as such, in this Pellegrino’s reference to the image of God is important. The *imago Dei* gives a foundation and justification for those human rights that form the basis of bioethical discourse: the right to autonomy, to truth, to assistance, to healing within the doctor–patient relationship. Benedict Ashley and Kevin O’Rourke state:

This indelible likeness to God constituted by the gifts of intelligence and freedom

opens all human beings to God's call to friendship. After we are reborn through grace, we are able to obey God not blindly, but intelligently and freely, recognizing that God has forbidden or commanded certain behavior. God's will does remain a mystery but it is not arbitrary, and its reasons should be explored. (Ashley and O'Rourke 2002, 7)

The person is a unified totality, a multi-dimensional creature with a body and an immortal soul. He or she is a corporeal being, an incarnated spirit. The body, including the mind, is integral to the person. It is not something simply to be utilized by the person like an instrument or tool. Its import does not rest on its perfection *in accidens* or its functionality. As such, the bodies of those with intellectual or other disabilities should not be objectified or treated as an instrument—least of all a “faulty one,” unworthy of the same respect as the non-disabled; rather, they should be understood as part of their whole person, worthy of the highest reverence. As the *Catechism of the Catholic Church* states:

The human body shares in the dignity of the “image of God”: it is a human body precisely because it is animated by a spiritual soul, and it is the whole human person that is intended to become, in the body of Christ, a temple of the Spirit. (USCCB 2014, para 363)

What are the consequences of this understanding of the person? First, every intervention on the body does not stop at the physical body but reaches the whole person. If I injure, mutilate, damage, manipulate, or kill the human body, I injure, mutilate, damage, manipulate, or kill the person; I lack the respect for the person himself. This is seen in the principles utilized in medical ethics, namely the Principle of Totality and the Principle of Bodily Integrity. The human body, by the mere fact that it is human, is a carrier

of meaning that points to the totality of the person, that “visible image of the invisible God.” The point of reference for all of morality is the human person. Cardinal Elio Sgreccia writes:

In front of any rational reflection, even lay or secular, the human person is presented as the point of reference, the end and not the means, the transcendent reality for economics, law, and history itself.... From the moment of conception to death, in every situation of suffering or health, it is the human person who is the point of reference and measure between what is licit and what is not. (Sgreccia 2007, 71)²

Second, the human person is gifted by being made in the “image of God,” but this gift implies a task. The person is a *steward* of his or her body. The point is perhaps even more obvious, and amplified, when a competent adult is the proxy-decision maker for the disabled child or adolescent. The most meaningful expression of this stewardship is his care for human life, inclusive of human sexuality. It is an integral part of the human vocation to desire to intervene on bodily dimensions of his person, but he or she must act, imitating the action of the divine model—with wisdom and love—responding with liberty and awareness of the dignity of human life. The concrete norms of action will be the result of a discernment that allows the moral agent to actualize in his concrete existence—lasting values that define the ethical truth of the person. Benedict Ashley and Kevin O'Rourke write:

Morality, in the ultimate analysis, is not a problem of obedience of rules, but it is an intelligent search for appropriate and concrete behaviors through which personal and communal goals are reached. (Ashley and O'Rourke 2006, 239)

Third, to the extent that the Christian has been incorporated into Christ in

baptism, he or she must acknowledge the primacy of Christ over his or her own desires, including sexual desires. Christian life is governed and ordered according to the Divine Plan. The flesh is the *salutis cardo*, the hinge of salvation, because making Himself flesh, the Son of God has united our flesh to his forever (Tertullian, *De carnis resurrectione*, 8, PL 2, 809). Christ has redeemed the body, and He is risen in the Flesh. The body is “a temple of the Holy Spirit” (Rom 6:19); it is the possession of the Lord and is part of the Lord. There is nothing further from the Christian faith than the disrespect for the body. Man and woman are called to respond to the evangelical call with their whole persons in their bodies. Such profound truths, which we strive to integrate into our own lives, are also a sacred responsibility when it comes to the teaching of our children. Christian sexual education within the family should have as its core an authentic anthropology that acknowledges the hierarchy of goods, so that when a child grows into adulthood he or she integrates the notion that “we belong to Christ, not to ourselves,” into daily life. In this way, sexual fulfillment is not a “right” or merely a pleasure—but can be sacrificed for a greater spiritual good if necessary.

For those persons with intellectual disabilities who retain decision-making capacity, or especially for those who are children and might temporarily or permanently have a proxy decision maker, even greater care is needed. The secular world describes sexuality among this population in value-neutral terms that assume, without critique, that sexual experiences among teenagers are a rite of passage that they are somehow being deprived of. The words of Dana Harader et al. are telling:

Furthermore, limited social interactions during middle childhood may hinder

adolescents acquiring sexual knowledge through interactions with peers. Since much sexual development is experiential in nature, this lack of peer interactions places adolescents with moderate disabilities at a decided disadvantage compared to their normally developing peers. The presence of a moderate disability can also affect the development of a sexual identity because sexuality is founded on intimacy and emotional contact, and provides a source of pleasure and emotional bonding with others (Murphy & Young, 2005). Adolescents with moderate disabilities may have an altered sexual self-image based on societal attitudes and a lack of knowledge, both within themselves and in their parents/caregivers. (Harader, Fullwood, and Hawthorne 2009)

A brief online search of “sexuality in teenagers with disabilities” provides links to Planned Parenthood’s sexual education “curriculum” for those with disabilities, as well as to the Planned Parenthood website; one prominent online “resource” provides a recommended link to a book with this title and description:

Enabling Romance: A Guide to Love, Sex, and Relationships for People with Disabilities (And the people who care about them) —by K Kroll and EL Klein; No Limits Communications. Addressing sexuality for disabled people, this book is particularly recommended for its attention to the sex education needs of youth with all types of disabilities. Its three main components include disabilities and sexual satisfaction; life and love with specific disabilities; and resource information for independent living, dating services, and publications. It offers a wealth of information on relationships and reproductive issues. (Advocates of Youth 2014)

By way of contrast, a Catholic anthropology offers persons with disabilities and their parents and caregivers a different path. During the celebration of the Jubilee

of the Disabled, Pope Saint John Paul II preached:

In your bodies and in your lives, dear brothers and sisters, you express an intense hope of redemption. In all this is there not an implicit expectation of the "redemption" that Christ won for us by his death and resurrection? Indeed, every person marked by a physical or mental difficulty lives a sort of existential "advent," waiting for a "redemption" that will be fully manifest, for him as for everyone, only at the end of time. Without faith, this waiting can be tinged with disappointment, and discouragement; supported by Christ's word, it becomes a living and active hope. (John Paul II 2000)

HUMAN DIGNITY AND AN OBJECTIVE SEXUAL MORALITY

As a community of believers, the truth of the dignity of persons makes demands upon us to work for justice for the vulnerable, and, in the specific case considered here, for those with intellectual disabilities. If the dignity of those children and adolescents with intellectual disabilities is equal to that of others, then society and the Church have an absolute obligation to address issues surrounding human dignity, including those surrounding human sexuality; if we do not, then society, and the Church with it, neglects the task associated with the gift of our dignity.

As we have suggested, the subject of sexual ethics for those with intellectual disabilities is ignored in modern manuals of moral theology, although there are some exceptions.³ The only subject treated with any depth is the morality of the sterilization of disabled persons (Smith and Kaczor 2007, 92–4).⁴ A sexual ethic for persons with intellectual disabilities begins with the foundation that has been outlined

above: the dignity of the human person. Those with intellectual disabilities have inherent dignity and should be treated as persons just like others in society. In pediatric medicine, therefore, children and adolescents with a spectrum of disabilities (and abilities!) ought be treated and counseled in a way which is informed by this same inviolable and immutable principle. The AAP has notably addressed sexuality in children, but based in an anthropology which is utilitarian and empiricist, lacking the communitarian element of personhood. The following observations address ways in which healthcare workers and educators in both seminaries and medical schools might confront issues of sexuality in bearers of disabilities. In this section, we are primarily addressing those children who are less severely affected by their disability—those children who will grow into adolescents and adults with mild-to-moderate intellectual disabilities.

At the outset, it must be emphasized that one must always maintain the clear distinction that is made in both moral theology and moral philosophy between the objective evaluation of the behaviors and the subjective responsibility of the individual involved. It is useful to recognize that each person is an individual and, therefore, it is difficult to develop specific guidelines that are valid for each and every person. This observation or premise is especially true when one speaks of issues of sexuality. For example, one person may be a paraplegic, and the physical, sexual issues may dominate. Another person may be blind; his disability does not affect his mental faculties, or the functioning of his sexual organs, but he will have to appreciate the beauty of another through different means. Still for another, it may be the case that he or she has an intellectual disability. The differing types and degrees of disability affect the approaches to addressing sexuality, *without altering the objective*

standards of morality. There are differences that both the pastoral minister and the pediatrician must consider, including the differing environments (communal and familial) of those with intellectual abilities and the differing degrees of sexual maturation. Within a seminary curriculum, these issues could be addressed within courses dealing with human development and pastoral counseling; within a medical school or clinical setting, a focus on the good of the whole person—their biological/medical good, the proxy's perception of the good (for children with disabilities), the good for the disabled as a human being, and their spiritual good—should be emphasized (Pellegrino 2005).

The Environment of the Person with Intellectual Disabilities

Though people have equal and inherent dignity, differences must be acknowledged. An important difference that cannot be neglected is the environment in which people with intellectual disabilities develop. The different levels of acceptance of persons with disabilities in communities will have some effect on a person's psychosexual development. Although communities today are more accepting than in the past, many still have a pre-established model of life in which certain values are higher than others. Some communities, for example, highly value material success; others value athletics; others value academics. Very few "value" disabilities, even if persons with disabilities are tolerated (Zavalloni 1984, 226). While one can appreciate a greater sense of welcome, of integration, and perhaps even of employment, this can also place those with mental disabilities at risk for manipulation, seduction, and sexual abuse (Vanier 2008, 2).

Specific consideration should be given to the family setting, which is decisive in

pediatric development. The type of family, the attitudes, expectations, and amount of assistance available can influence, positively or negatively, the overall development of persons with disabilities. A person with a disability might be overprotected, might not be encouraged, or might be deemed totally incapable (Zavalloni 1984, 226). Moreover, an unstable family environment can increase the difficulties for an adolescent or adult with disabilities to heal internally. Vanier reflects:

A wound in the body heals naturally if the body is healthy. But the heart cannot heal itself. It needs to be surrounded by others who can call the person out of the fears that paralyze the heart and into a world of trust and openness with others. In order to find an inner harmony and to be at ease with his masculinity, the adolescent or man with a disability will need the presence of men who are at ease with their own masculinity—this means those who are able to have simple, open, true and unifying relationships with women without dominating them or being dominated by them, who are able to recognize in women their gifts and qualities which are different from their own. The same, of course, holds true for women in order to be able to discover their own femininity. (Vanier 2008, 26–7)

One must also take into account the current cultural context. The state of mass media makes addressing sexual issues urgent. In developing a general orientation, one must account for the challenging media-dominated environment of the new millennium. Vanier describes this challenge:

Over the last twenty-five years, the media and Internet have developed a great number of films and DVDs which portray sexuality in a superficial and sometimes pornographic way. Sexuality has not been portrayed as a gift that

grows out of a permanent relationship and strengthens and defends the relationship. People with a learning disability can be confused by these films. They can be seduced into sexual relationships without an awareness of the consequences or the capacity to assume responsibility for a partner. (Vanier 2008, 2)

Although this article cannot take into account all environmental variables, one final variable deserves attention. It is said that society is more accepting of people with disabilities, yet we must acknowledge that there still exists an attitude that views the sexual needs of persons with disabilities as a type of taboo or which refuses even to acknowledge that persons with disabilities have such needs (Sgreccia 2006, 475). This may be seen as a point of agreement between the AAP and Catholic ethicists, for example. Zavalloni contends that the mass media's constant emphasis on esthetic beauty may contribute to society's picture of the disabled person as a non-sexual person, which in turn leads to sexual repression (Zavalloni 1984, 228). Sgreccia (2006, 475) sees another possibility: the negative attitudes of the social context can be reflected onto the handicapped person and may create in some way a type of fragility and insecurity, which may then manifest itself even with compensatory (negative) behaviors.

Either response may lead to the isolation of those growing up with intellectual disabilities and may deprive them of the proper community which they need to support the development of healthy relationships. Imposed isolation and solitude is the end result. Vanier contends that what is necessary for proper psychosexual development in those with disabilities is community, the place of encounter, and sexual integration (Vanier 2008, 91–107). Consequently, one must support the possibility and the opportunity for the unassailable right to establish

relationships of friendship and engagement for all the handicapped that are able to validly contract marriage (Sgreccia 2006, 475). For those who cannot, the caregivers must still promote an environment in which relationships—friendships, non-sexual physical contact, esteem “coaches” and mentors—can flourish and allow the child or adolescent with disabilities to reach his or her potential. Children with profound disabilities cannot be treated as objects to be “guarded” or hidden from others, nor can they be assumed to be so unaware that apathy prevails.

Reaching Maturation and the Covenantal Encounter

A foundational issue for those children and adolescents with disabilities is that they must be helped to reach the adult maturation, in the areas of affectivity and sexuality, to which they have a right and of which they have a need, each within the limits of his or her capacity. For which, the scope of affective education needs to include developing the capacity of oblation (i.e., self-giving, sacrificial) love, which is proper to all men and women and which is also valid for the disabled (Sgreccia 2006, 475).

Recent Magisterial teaching in the area of human sexuality and marriage, especially after the Second Vatican Council, has rightly emphasized the role of conjugal love in marriage. This love is to be total, human, faithful, and fruitful. Pope John Paul's *Theology of the Body*, in a particular way, emphasizes the necessity of the total gift of self. Love is the starting part of human growth but all love, especially oblation love, requires a pedagogy, which begins in childhood.

Many with intellectual disabilities are wounded and experience anxiety and

rejection, whether by family members or by society. These wounds can be healed by the experience of love in relationships. Some may wonder whether such love is possible. For this reason, at an early age, inasmuch as possible, children with disabilities must be assured of God's absolute love. Though they may not be able to enter into relationships deeply with others at a high cognitive level, they can be reminded of the covenantal and absolute love of God, who is faithful; who is forgiving; and who comes to us even when we have difficulty striving for Him. By experiencing this relationship with God, a child realizes that covenantal love is possible with parents and others. Relationship is not based on intellectual ability but upon covenantal encounter. Where there is a relationship with God, it is easier for the child to live in relationships with others (Vanier 2008, 21). It is for this reason that Baptism and Eucharist are so significant in the lives of those with intellectual disabilities; they establish and nurture loving relationships with God and the Church.

For the doctor who cares for children with disabilities, it should be emphasized that one's greatest therapeutic instrument is *oneself*. How will the physician use herself to heal, to help, to make whole this child in front of her? If the discovery of the truth of a person's dignity is made through encounter—through relationship—then building that relationship through touch, respect, and compassionate communication at the appropriate developmental level are all crucial. Seeing the child as a person rather than a "problem" becomes paramount. Respect and patience with the parents or caregivers is also important, as one negotiates a shared view of the best interests of the child, taking into account their *wholeness* and sanctity as a person.

This education requires time and patience. It demands love, forgiveness, and

a constant affirmation of those with disabilities. At the same time, it requires the exercise of authority by parents, physicians, and medical educators; it demands knowing how and when to restrict or permit an action, with the goal being freedom from behaviors that enslave or that are merely instinctual. For example, interventions to limit public masturbation by people with disabilities often define "success" as simply controlling the "public" part. Masturbation in private is permitted or even encouraged (Tarnai 2006). Since sexuality has its true meaning in the order of marriage, one may not legitimize absolutely, or worse, encourage casual and libertine exercise of sexuality (Tarnai 2006; see also Vanier 2008, 228). This permissiveness would not be within the lens of the authentic good of the person and one would not be speaking of an authentic love. To suggest or assume that an intellectually disabled person could never control his or her sexual urges is to assault the dignity of the person by comparing the person to an instinct-driven beast. In those with profound disabilities, or even some with severe autism spectrum disorder where compulsive behavior is difficult to control, the situation is more complex. Behavior may appear to be sexual, but, lacking a willful element, restriction should be less focused on the "moral" action *per se*, because sexual appearing actions are more akin to conditioned, instinctual acts. Instead, love of the person should motivate the caregiver or physician to devise strategies to redirect, and to consider pharmacological approaches if necessary, for the safety of the individual and others, and to preserve the good of public decency.

Therefore, sometimes this educational growth requires very directive action—telling someone that this action or that action is wrong (not good for them as persons) and attempting to explain why it

is so (if they are able to understand), or by encouraging medically *and* morally appropriate behavior in a supportive environment rooted in love. Love demands truthfulness, often the hard path and not the “quick fix.” Other times, those with authority need to recognize when it is appropriate to step back and allow the individual to exercise his or her freedom within a safe environment.

The foundation of sexual education therefore cannot be merely the physical components of genital sexuality. Biological facts are important, and these should be taught to those with intellectual disabilities by the family inasmuch as they are able to understand—for their good and for their safety. Nevertheless, authentic sexual education needs the foundational context of a covenantal relationship. Learning how to give and receive love through affective friendship is a pre-requisite for considering marriage in the future and genital, sexual activity. A healthy marriage, rooted first in friendship, requires knowledge of oneself and of an openness to be enriched by knowledge of another. Thomas Aquinas saw marriage as the “greatest friendship” (Aquinas, *Summa contra Gentiles* III, 123.6; Noonan 1976). For those children who will be incapable of marriage, the example of unconditional loving friendship is nevertheless an experience for which they have a right as a member of the *communio personarum*.

Sterilization of Children and Adolescents with Intellectual Disabilities

The fundamental equality of persons, rooted in each person’s inherent dignity, means that the values that preside over the sexuality of a healthy person are the same as those that guide and govern the

sexuality of a disabled person. The Italian moralist Lino Ciccone writes:

There does not exist, nor could there, a *sexual morality of the handicapped different from that of the healthy*. This is one of the logical consequences of the affirmation that the handicapped are human persons like all others. To configure for the handicapped a different morality, would be to say once again that they are “different”, and really in a fundamental aspect of human existence such as human sexuality. This position rejects not only of every form of libertinism but also of every arbitrary restriction. (Ciccone 1987, 127 [original emphasis])

The question of human sexuality for those with intellectual disabilities that is often discussed is that of sterilization. Although the “Ashley treatment” is an extreme case, discussions usually take place within the realm of medical (philosophy) or sexual (theology) ethics. Typically, there are two versions of this question. The first considers whether it is morally licit to put an intellectually disabled adolescent on some form of contraception or to have her sterilized to prevent her from having children. Sometimes, the motivation for doing so is clearly eugenic—those in authority do not want to “pass on” a child’s “defect” to subsequent generations, which would lead to some kind of unacceptable “cost” (usually economic) to the rest of society. In other words, it would make no difference whether or not this was an adolescent or an adult; the real issue is the bio-psycho-social makeup of the individual. A recent article in a prominent medical journal—while not addressing the disabled directly—argued for easier access to immediate post-abortion sterilization for (mostly poor) women. This was purportedly not only to “benefit” them, but also to benefit society economically, given the future healthcare costs of this population and their babies (Krashin et al.

2014). The not-so-subtle eugenic thinking would apply *a fortiori* to disabled young adults.

But sterilization may also be couched as an issue of “child welfare.” Not only do some not want children or adolescents with disabilities to “suffer the consequences” (pregnancy) of possible sexual abuse,⁵ but it is also thought that the parent could not have truly consented to intercourse, and would not have the cognitive ability nor the resources to care for and nurture this child, particularly when she struggles to care for and to make good decisions for herself. The second version asks whether it is licit to place a young woman with intellectual disabilities on a contraceptive or to have her sterilized if she is at risk of being sexually abused.

Church teaching on sterilization is well known: contraceptive or direct sterilization is intrinsically immoral; no good intention can ever make the act good (*Catechism of the Catholic Church* 1997, n. 2399; Paul IV 1968, n. 14; United States Conference of Catholic Bishops 2009, dir. 53). In the first form of the sterilization question, as in the case of *Buck v. Bell*, there is often an underlying eugenic mentality. “Three generations of imbeciles” was enough for Justice Holmes. The mentality was that for the good of public health and to “purify” the gene pool, certain members of society should be forcibly sterilized. This would have the additional effect of saving the state resources for caring for adults and children with intellectual disabilities. Some theologians, using the faulty theory of proportionalism, argue that preventing such births would be a greater good for the individual and society than the evil of sterilization. Others attempt to argue that the principle of totality can be utilized to justify direct sterilization inasmuch as the pregnancy may be hazardous to the health of the mother or may result in the birth of a child who will suffer from a disability,

possibly severe; thus, sterilization comes to be seen as something good for the person’s well-being and for that of his or her family. Such thinking must be rejected; the price to be paid for such well-being for the person with the disability is his or her fertility. He or she is made in God’s image, and that creation is good; the body cannot be arbitrarily mutilated; rather, according to the proper interpretation of the principle of totality, such an intervention could only be permitted if the operation was necessary to protect the life and health of the person (Haas 1995).

Sometimes it is not a question of voluntary sterilization, which though immoral, is legally permitted; it is a question of “forced” sterilization, through coercion and manipulation by those with authority. Consider another Supreme Court case *Stump v. Sparkman* (1978). This was a judicial immunity case in which Judge Stump granted a mother’s petition to have her fifteen-year-old daughter subjected to a tubal ligation, solely on the mother’s testimony that the girl was “somewhat retarded” and associated “with older youth and younger men.” The daughter, Linda Spitler, was told that she was having her appendix removed; therefore, she was neither informed, nor did she ever give informed consent. Later when she married Leo Sparkman and could not conceive, it was discovered that she had been sterilized. She and her husband attempted to sue the judge, but eventually, the Supreme Court ruled that judicial immunity applied. Judge Stump was immune. Linda Spitler Sparkman was left without a judicial remedy and was deprived of her fertility.

The *Stump v. Sparkman* case illustrates the gross violation of human dignity to which those with intellectual disabilities may be subjected. It demonstrates how vulnerable those with even perceived intellectual disabilities are in society; on the mere suspicion (not proof) of being

“somewhat retarded,” Linda Spitler Sparkman was sterilized. Her dignity was violated in numerous ways. She was not granted due process under the law; she was not seen as having *equal* human dignity. In violation of the first principle of the Nuremberg Code (<http://www.HHS.gov>), she was not afforded the opportunity for *informed consent*, reasonably free and adequately informed consent. Her *bodily integrity* was violated, which is a further violation of her human dignity. Her dignity was further violated in that she was denied the opportunity to become a mother through sexual intercourse with her husband, who was also denied the opportunity to become a father through intercourse with his wife. All of this occurred because those with authority, a judge and her mother, deemed that they had the right to decide what was best for a person with perceived intellectual disabilities.

It should be noted, in particular to the secular world, that the Catholic Church has always rejected such thinking, in favor of unconditional love and special care for the dignity of persons with disabilities. It did not take the horrors of the eugenics movement in the twentieth century, nor the atrocities against the disabled during World War II for the Church to become “enlightened.” Thus we plainly see a distinct advantage in setting a place for the Church and her members in the public square, to engage courageously in dialogue with those who differ, and to protect and actively promote a “sacred space” for the disabled in society.

Although “sensational” cases such as *Stump v. Sparkman* are less likely today to be adjudicated in the courts, the rise in requests for the “Ashley treatment” should give us pause. Is this a new form of “forced sterilization,” guised in a “best interest” standard? Are physicians and the parents of some disabled children replacing the judge as the “supreme authority,”

deciding who is “fit” and who is “unfit?” In bioethics, a “forced sterilization” would imply that the consent of the person was not given, that her autonomy was violated in favor of another good. Since disabled adolescents, even high functioning ones, cannot legally consent, one could argue that they can never be “forced” to do anything. Yet, the “best interest” standard used in pediatrics presumes that the proxy decision maker (the parent) with every decision affirms the “dormant autonomy” and dignity of the child in question; the decision is made *for that person* alone—not society, not the parents, not any other good. Sterilization, which violates the principles of totality and bodily integrity, cannot be in the adolescent’s “best interest.”

However, some might counter that it is licit to place a woman with intellectual disabilities on a contraceptive or to have her sterilized if she is at risk of being sexually abused. Then it might be in her best interest to temporarily or permanently prevent conception. The risk of sexual abuse of those with intellectual disabilities is high (Barger et al. 2009; Firth 2001; McCormack et al. 2005; Murphy and O’Callaghan 2004; Peckham 2007; Servais 2006). There are some, like Carrie Bell, who are victims of violence within foster families. There are others who are susceptible to sexual violence in a residential facility, from other residents or employees. There are still others who dream of marriage and children and, due to their intellectual capacities and lower self-esteem, are easily seduced and violated. Could someone with an intellectual disability, who is *likely* to be a victim of sexual abuse, be placed on contraceptives as a means of self-defense against acts of violence and sexual aggression? Although it is a disputed question, there is historical precedent within Catholic theological reflection to act in this way in the context of sexual oppression, even within marriage,

precisely because the victim or potential victim is not intending a venereal or contraceptive act, nor is she giving consent to a sexual act. The object of her choice is not to contracept; she does not wish to engage in a sexual act. She is considered to be defending herself against (possible) violence and against the perpetuation of an act of aggression (Aertnys and Damen 1967, 289–90; Bayer 1982, 154–75; Long 2007, 106–7; Napier 2010; Tollefsen 2010; Zalba 1968).⁶ Again, the distinction between *objective* morality and *subjective* culpability must be remembered for in such cases the amount of freedom involved in the action may be severely limited or even absent.

As alluded to previously, sterilization and contraception as “solutions” to the problem of sexual abuse in those with disabilities are really not solutions at all. First, since the implication is that the subject is so mentally disabled that he or she cannot consent to birth control for his or her own “protection,” such procedures amount to a kind of forced sterilization or contraception. Even the United Nation’s Committee on the Rights of the Child has suggested that forced sterilization on the disabled child is to be considered an “act of violence”:

The Committee emphasizes that the interpretation of a child’s best interests must be consistent with the whole Convention, including the obligation to protect children from all forms of violence. It cannot be used to justify practices, including corporal punishment and other forms of cruel or degrading punishment, which conflict with the child’s human dignity and right to physical integrity. An adult’s judgment of a child’s best interests cannot override the obligation to respect all the child’s rights under the Convention. (United Nations Committee on the Rights of the Child 2011, General Comment 13)

There are other serious risks to the inherent inattentiveness within the “contraceptive imperative.” If sterilization or contraception might mask abuse while preventing pregnancy, they also might increase the risk for contracting sexually transmitted infections, including HIV, from abusers. Sexually active individuals with intellectual disabilities, for a variety of reasons, are already at a higher risk of contracting sexually transmitted infections (Servais 2006). The same kind of “false security” of hormonal contraceptives which puts normal-intelligence teens at higher risk of obtaining sexually transmitted infections (CDC 1996; Middleman et al. 1997; Tyler et al. 2014) might also affect the abuser. The teen, with mild intellectual disability, who “consents” to contraception, might be confused about the kind of “protection” sterilization or contraception offer. For example, in one study, 68 percent of intellectually disabled persons thought that oral contraceptives decreased the risk of contracting AIDS (McGillivray 1999).

The problem of sexual abuse of those with intellectual disabilities highlights the need to give further consideration to environmental and safety protocols that ensure the protection of those with intellectual disabilities. The focus should be on preventing sexual abuse by strengthening training and screening of caregivers, increasing penalties, and recognizing tell-tale signs of abuse by healthcare providers, rather than on knee-jerk “sterilization as the solution” to the failure of those protocols, often viewed as inevitable.

PRACTICAL IMPLICATIONS

In this paper, we have argued that sexuality in the young with intellectual disabilities should always be viewed through an anthropological lens which is

rooted in inherent dignity and ultimately moves beyond sexuality as a “biological problem” to be dealt with; rather, understanding that—for the disabled and for ourselves—our bodies are not our own, and that there are spiritual goods beyond sexual goods, we can begin to focus on deepening a covenantal approach to love due every person with a disability.

What practical steps can be taken from such a view? First, *education* in both seminaries and within the medical profession must endeavor to embrace disability, including issues of sexuality, head on. We must not shy away or be embarrassed by it. We must dig deeper within medical and theological education than that oft-repeated mantra “the disabled person has inherent dignity.” If we truly believe that, we must follow it where it leads. What can we do to engender respect and empathy for these children and their parents among our students? How can we open gates that allow the uninitiated to actually experience the *presence* of a person or family with a disabled child? One example might be to arrange for seminarians and medical students to have early and longitudinal exposure to disabled children (especially the profoundly disabled) and the families that care for them. The tools for both secular and religious bioethical analysis; pedagogy rooted in natural law and theological reflection, yet informed by the literature in the field of medical education; and research on disability in medicine, psychology, and psychiatry should be utilized and advanced by the Church and her followers.

Second, *clinical practice* should incorporate the healing of the *whole person* in her integrated biological, psychological, social, and spiritual self. Practices such as the “Ashley treatment,” reflexive contraception for the disabled, or eugenically motivated sterilization should be rejected. However,

well meaning the motivations of their proponents, the developing sexuality of the disabled adolescent and the difficulties associated with it should be viewed not as a problem with a simple fix, but rather as a profound challenge to our own comfort, and an opportunity to further sanctify ourselves through the hard work of respecting dignity and protecting the vulnerable in ethical ways.

Third, *advocacy* for the disabled in society should be a duty, not an option. A discussion of the historical treatment of the disabled person shows the special value of an authentically Catholic bioethics in the public secular square, and what we as a Church can offer the world. Although many (perhaps most) do not agree on “first principles,” the truths of the Gospel have always been available to be grasped by man through reason. We must therefore try to advocate, within public policy and law, ethical principles compatible with Catholic teaching, for the sake of those treated as the “least of these.” We should not retreat to the dwindling enclaves of believers within Catholic hospitals or medical practices. Catholicism, and Catholic bioethics in particular, must remain evangelical, a “light in the darkness,” possessing an optimism which no darkness can comprehend.

Finally, just as we must have courage to teach the world, we must have courage to learn from it as well. We cannot simply ignore statements from the AAP or proportionalists, or utilitarians (or even modern-day eugenicists!). Committing the “genetic fallacy”—that is, rejecting something not on its merits but simply because of where it came from—would not serve ourselves or the disabled well. Research and position papers in theology and medicine (including those hostile to Catholic teaching) should nevertheless be studied, critiqued, and challenged, and be allowed to challenge our worldview and us. In this

way we will learn something, and we will also better be able to teach something in the future.

The subject of human sexuality and those with intellectual disabilities has long been neglected. The Church has a special duty to reflect theologically and to act in light of that theological reflection to affirm and protect the dignity of persons with intellectual disabilities. There is much more to be learned about this issue. Pediatricians and those in the healthcare field must be inspired by the experience of the dignity of such persons to pursue medical care which accounts for not merely the biological or public good alone—but instead for that sacred good constituted by the totality of the disabled person. Within their respective competencies, the Church and modern medicine can continue to learn from one another, inform one another, and where disagreement exists, search together for paths that lead to the upholding of human dignity.

In his concluding remarks to those gathered for the international symposium on “The Dignity and Rights of the Mentally Disabled Person,” Pope Saint John Paul II eloquently stated:

Disabled people are living icons of the crucified Son. They reveal the mysterious beauty of the One who emptied himself for our sake and made himself obedient unto death. They show us, over and above all appearances, that the ultimate foundation of human existence is Jesus Christ. It is said, justifiably so, that disabled people are humanity’s privileged witnesses. They can teach everyone about the love that saves us; they can become heralds of a new world, no longer dominated by force, violence and aggression, but by love, solidarity and acceptance, a new world transfigured by the light of Christ, the Son of God who became incarnate, who was crucified and rose for us. (John Paul II 2005, 5)

We must not forget then, perhaps the most important point—that much too can be learned from those with intellectual disabilities, from their history and their experiences, and from our experience in loving them as our brothers and sisters. Physicians and theologians alike are used to prescriptions, but no prescription will begin to heal the body or the soul unless one truly *listens* to the person and invests oneself in solidarity with another.

ENDNOTES

1. Underscoring the neglect of this issue, the message did not even appear in the English Weekly Edition of the paper.
2. All translations into English from Italian throughout are our own. English translation of Jean Vanier, *Homme et Femme Il Les Fit* (Paris: Editions Fleurus) has appeared under the title *Man and Woman God Made Them* (New York: Paulist Press, 2008).
3. The subject is taken up in Elio Sgreccia, *Manuale di bioetica, vol. II: Aspetti medico-sociali* (2006: 474–6). Recently, an updated English translation of Jean Vanier, *Homme et Femme Il Les Fit* (Paris: Editions Fleurus) has appeared under the title *Man and Woman God Made Them* (2008); this is a thorough treatment of the question. Father Roberto Zavalloni, O.F.M. addressed seminary formators on this subject in his article, “Il problema dell’uomo umano negli handicappati” (1984).
4. The specific question the authors take up is: “Would it be moral to put a mentally handicapped woman on a contraceptive or have her sterilized if she is at risk of being sexually abused?”
5. Of course, unintended pregnancy is only one possible consequence. Sterilization is not a “quick fix” for the emotional, physical, and psychological toll of sexual abuse. As we suggested earlier, it may even make sexual abuse more tempting to the perpetrator since it hides one serious marker of the abuse.
6. Bayer provides an excellent description of the development of Catholic doctrine from the seventeenth century through the

late twentieth century, including an examination of the opinions of theologians regarding the use of prophylactic anovulants to prevent pregnancy, initially in the cases of the rape of religious women after the events in the Belgian Congo around 1960, and later in the cases of sexual oppression within marriage.

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BIOGRAPHICAL NOTE

Earl K. Fernandes, S.T.D., Athenaeum of Ohio/Mount St. Mary's Seminary of the West. His email address is efernandes@athenaeum.edu.

Ashley K. Fernandes, M.D., Ph.D., The Ohio State University Center for Bioethics and Medical Humanities. His email address is ashley.fernandes@osumc.edu.