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

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**Ethical Practices and Policies in the Health Care of People
with Intellectual and Developmental Disabilities and Their
Families**

Framing the Issues

William F. Sullivan, University of Toronto, Canada
John Heng, King's University College, Canada

Abstract

This paper seeks to provide various building blocks for the development of an ethical framework to guide practice and policy in the health care of people with intellectual and developmental disabilities (IDD). First, different models of care are critically reviewed. Next, the significance of meaningful and loving social relationships is emphasized. Health care

providers are encouraged to “be with” people with IDD and their families rather than merely doing things “for or to” them. In supporting decision-making of people with IDD, health care providers should take into account the capacity of such persons to apprehend values, the importance of knowing the individual well, and the helpful role that the individual’s family and other communities that give care can play.

Keywords: intellectual disability, ethics, health policy, ethical framework, models of care, human rights, patient relationship, supported decision-making

Introduction

During the last four decades, the health care of people with intellectual and developmental disabilities (IDD) and their families has changed significantly in many countries. People with IDD are surviving to adulthood and old age in greater numbers than in the past. More of them reside, learn, work and enjoy leisure in their communities instead of being segregated in large institutions on the periphery of society. Increasingly, health care is being offered to people with IDD in hospitals and clinics that serve the general population.

These changes necessitate the development of a new ethical framework that can guide the provision of health care for persons with IDD as well as policies regulating such care. In this article we intend to provide several building blocks for such a framework.¹ First, we review the normalization principle that has enabled much of the improvement in the care of persons with IDD in the latter half of the twentieth century. We then compare and contrast this model of care with its main competitor that focuses instead on the biological causes of IDD. Having thus achieved more clarity about the ethical challenges that present themselves in the care of persons with IDD, we briefly discuss three specific concerns for health care providers: recognition of the human rights of persons with IDD, the importance of encounter, and respect for their unique agency.

Normalization

The aforementioned shift towards community care has been made possible, to a large extent, by the acceptance by public policy makers of the “normalization principle,” which was first proposed in the Scandinavian countries, and later in the United States and Canada, by Niels Bank-Mikkelsen, Bengt Nirje, and Wolf Wolfensberger. As Nirje formulates it, normalization entails making available to people with IDD “patterns of life and conditions of everyday living that are as close as possible to the norms and patterns of the mainstream of society” (179). Similarly Wolfensberger promotes care of people with IDD through “utilization of means which are as culturally normative as possible in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible” (28).

¹ This article is based on a presentation at the VIth Colloquium of the International Association of Catholic Bioethicists that was held in Rome, Italy in the summer of 2013, and that focused on twenty-first-century ethical practices and policies in the health care of persons with IDD. In that presentation, we sought to frame the issues for the remainder of the conference. The present paper is informed by the work accomplished in those subsequent days of listening, reflection, and discussion.

Underlying the normalization principle is the philosophical assumption that limitations experienced by people with IDD only arise in the interactions with their physical and social environments and are to a large extent induced by those environments. This fundamental idea has been elaborated into what is called the “social model of disability.” The normalization principle proposes a specific application of this model, holding that the better people with IDD are helped to adapt to their communities, the less conspicuous their disabilities will become, and consequently, the more enhanced their experience of life will be and the greater their opportunity to enjoy the rights and access to services to which others in the community are entitled. The normalization principle has been applied to identify and address disparities in health care between people with IDD and the general population, and barriers to health information and services that people with IDD experience.

While the normalization principle continues to be widely accepted today, particularly in the social sciences and among public policy makers, it has its critics. First, some point to research that normalization has not necessarily promoted significant inclusion and participation of people with IDD in their communities. Many of them, as well as their families, continue to experience the negative attitudes of other people in society, ridicule, discrimination, and isolation. They still are seldom consulted regarding decisions that affect their lives and their health care. Many live in poverty, which tends to have adverse effects on health. Neglect, abuse, and trauma are prevalent among people with IDD, and individuals known to them in their “normalized” settings are often the perpetrators.

Second, by aiming to make the differences between people with IDD and the general population less conspicuous, practices and policies of normalization have rendered some of their health needs and issues less visible to health care providers. This is especially true of individuals who have profound disabilities and those with multiple and complex needs. There is a growing awareness among health care providers that the health and experiences of people with IDD are enhanced not only by improving their access to generally available health information and services, but also by attending to those health needs and issues that are different from those of the general population. This reality is recognized by the United Nations’ *Convention on the Rights of Persons with Disabilities*, which promotes their right not only to “the same range, quality and standard of free or affordable health care and programs as provided to other persons” but also to “those health services needed by persons with disabilities *specifically because of their disabilities*” (article 25 a, b, emphasis added). Disorders in health, including mental health, among people with IDD might be more or less prevalent, have a different age of onset, severity, and progression, and manifest differently than in members of the general population. People with IDD often have difficulty communicating their experience of pain and other distressing symptoms and might relate these through changes in behavior. Many of them also require support from family and other close caregivers to make decisions regarding their health care. Recognition of these realities has led health care providers to develop clinical guidelines for primary care that are adapted to the particular health needs and issues of people with IDD (Sullivan, Berg, and Bradley).

Biomedical Model

In addition to the normalization principle, another conceptual model has been prevalent in guiding the provision of health care to people with IDD. This model, generally called the

“biomedical model” is based on the philosophical assumption that the cognitive and adaptive impairments of people with IDD, and their characteristics and behaviors, are either exclusively or primarily determined by genetic and other biological factors that vary from the norm. Interest in the hereditary basis of some conditions associated with IDD, for example, has been accentuated recently by the complete mapping of the human genome and the hope that some scientists will eventually discover the genes responsible for the anatomical, physiological, intellectual, and behavioral features or phenotypes that are associated with various disabilities. In this model, the role of health care providers is to identify these disorders and to address them through some biomedical intervention if possible.

The biomedical understanding of IDD focuses interventions not on patients as persons, but on the “anomalous” diseases and disabilities that they have. This approach to caring for people with IDD allows for a separation between the person and his or her disability and thus decreases the chances that a person is identified only with and reduced to his or her disability. It also has been appropriate and effective when treating certain health issues that have often been overlooked in the normalization model.

However, health care providers who regard every health issue as reducible to a biological basis can overlook holistic assessments and therapies that might be relevant and helpful in some instances, less restrictive or intrusive, more easily tolerated, and more balanced in terms of the likelihood of greater benefits and fewer harmful side-effects for both the patients and their families. That is, they neglect the many positive possible supports and interventions that are non-biomedical. For instance, prescribing anti-psychotic medication to treat distressed behaviors in people with IDD now appears widespread even when these persons do not have a psychotic illness (De Kuyper, Hoekstra, and Visser). More nefarious still are proposals that are eugenic in nature. The reductionist version of the biomedical model has been used by some to support the idea that conditions for which biomedical treatment is presently limited should be eradicated through genetic testing followed by selective embryo destruction or termination of pregnancy, and that the possibility of their transmission to progeny should be prevented through sterilization.

Both the normalization and reductionist biomedical models are inadequate as an ethical framework for the health care of people with IDD because they focus too narrowly on some aspect of their lives and conflate that aspect with the whole. More problematically, both models are based on the philosophical position that the quality of life of a person with IDD varies according to the extent to which he or she fits in with what others, often without such disabilities, judge to be the social or biological norm. If guided by these models, the attention of health care providers tends to be channeled toward interventions that promote what is “normal” without critically assessing the basis of those norms and changing the discriminatory attitudes and behaviors that might follow from them. For example, Peter Singer has argued that any human being who lacks rational self-consciousness is not a “person” and is not entitled to the ethical and legal rights afforded to persons. Relative to this criterion, people with IDD will always be at a disadvantage. Neither the normalization nor the biomedical models grow out of the conviction that people with IDD have inherent or intrinsic worth that does not depend fundamentally on, or vary according to, what other people in society judge to be their worth. Although neither model takes an explicit stance on this issue; they do not provide adequate ethical grounds for health care that seeks to protect

and promote the life, well-being, and flourishing of people with IDD who have been, and still are, especially vulnerable to the negative evaluation of people without such disabilities.

The Intrinsic Worth of People with Intellectual and Developmental Disabilities: Human Rights and an Ethic of Love

An alternative ethical framework for guiding health care of people with intellectual and developmental disabilities emphasizes universal human rights. Such a framework is grounded on the philosophical position that all human beings have certain inalienable rights and also the corresponding duty to respect the rights of other human beings and to conduct themselves accordingly. Since people with IDD are members of the human species, they too enjoy these inalienable rights.

The participants in the 2013 VIth Colloquium of the International Association of Catholic Bioethicists affirmed this philosophical position in their consensus statement (reproduced in this supplement of the *Journal of Religion and Society*):

Every human being has intrinsic dignity and equal worth. These do not vary according to an individual's characteristics, abilities or experience of life. The position that certain human beings, namely those with severe cognitive impairments, lack dignity and worth should be rejected (Principle A.1).

They also concluded, however, that an ethical framework based on universal human rights and corresponding duties, while it elaborates on an important insight that ought to be supported, still does not draw out the full implications of the position that every human being has intrinsic dignity and is equally entitled to optimal health care regardless of the presence of any IDD.

First, like the normalization and biomedical models, a human rights framework does not point to the necessity of attending to the individual characteristics of the subject of rights to whom one has the duty to provide care. There is a tendency within a universal human rights framework to regard each human being as like any other human being. This view is correct in reference to a person's possession of certain inalienable rights and certain ethical duties, but incomplete in that it fails to consider the particular characteristics of the individual that should inform good health care for that person.

Second, and ironically in the opposite direction, an ethical framework based on universal human rights has the tendency to emphasize individual rights. While this is an important emphasis when health care providers advocate on behalf of individuals who are at risk of having those rights infringed upon by other individuals or by the majority in society, it can cause health care providers to overlook the important supportive role of an individual's community and the positive impact of human relationships in promoting the human rights of their patients. In the health care of people with IDD especially, what family members and other regular caregivers offer to them, and correspondingly, what they offer to their caregivers, are crucial dimensions of that care.

To amplify our understanding of the intrinsic worth of all human beings as the basis for ethical health care of people with IDD, it is thus necessary to move beyond the limitations of a human rights approach. One way to achieve such amplification is to draw on Christian

teachings and reflections. For example, the aforementioned consensus statement insists, in reference to *Gaudium et Spes*, the Second Vatican Council's Pastoral Constitution of the Church in the World, that

[f]or Christians, every human being is made in the image and likeness of God. Each human being, without exception, is known and immeasurably loved by God. Each has a role in the building of God's kingdom in the world and is invited to participate in everlasting communion and happiness with God (Principle A.2).

In reference to Pope Benedict XVI's 2005 encyclical letter *Deus Caritas Est*, the consensus statement next elaborates:

Christians affirm that the capacity in humans to love and be loved is based on their creation in the image and likeness of God, who is love (*caritas*). Through God's gift, human beings are invited to participate in loving communion with God and with other human beings. Christian love or *caritas* does not depend [entirely] on the reciprocity of the one being loved but stems from a personal encounter with the self-giving love of Jesus Christ and a regard of all human beings, from the perspective of Christ, as God's beloved children and my brothers and sisters who desire to be loved as much as I do (Principle D.11).

The theological insights offered in these points – that each human being has intrinsic worth, both as a unique individual with a meaning and purpose for existence, and as inherently relational and belonging to the human family – complement and build upon the human rights ethical framework. The focus on rights and duties is amplified to include the Christian concept of love (*caritas*), which supplies the motivation and shapes the attitudes of the one providing health care. It also expands on the notion of justice to include other equally significant ethical notions such as connectedness and mutual interdependency of human beings.

“Doing For or To” versus “Being With”: Friendship, Solidarity, and Agency

Notwithstanding their fundamental differences, all of the models of health care for persons with IDD discussed so far share a common presupposition. As is true of virtually all of health care ethics, these models seek to guide health care providers in what they should *do for or to* their patients. Virtually absent is a consideration of how they should *be with* their patients, that is, how to be attentive to them as individuals with needs but also as people who, with their families and other regular caregivers, can be partners in care with something unique and valuable to offer in and through their experiences of disability. Jean Vanier, the founder of the international L'Arche communities, has consistently challenged health care providers to create an ethics of “being with” people with IDD. In a similar vein, the Dutch ethicist Hans Reinders has called on care givers to consider the importance of friendships and other meaningful social relationships in promoting the personal dimension of inclusion

of people with IDD in society, which goes beyond the political dimension based on law and public policy.²

Such a framework does not gloss over the limitations and suffering that people with IDD and their family's experience. It addresses the important question of how health care providers should respond when faced with the incapacity of medicine to overcome these limitations completely or even adequately.³ It guides them to develop the dispositions and virtues necessary to encounter and show solidarity with their patients with IDD and their families, to work in partnership with them to promote whatever is possible to enhance their situation, and to be receptive to what people with IDD have to offer, even and especially those with profound limitations. Simply by being in need, persons with IDD can draw health care providers and caregivers into solidarity with and heartfelt concern for another human being. They remind all of the inherent frailties and limitations of the human condition, but also that meaning, healing, development of character, and spiritual growth that can nevertheless be found and experienced through acceptance of these frailties and can transform the individual and those surrounding him or her.⁴

The aforementioned emphasis on concern for the vulnerability of persons with IDD entails the risk that caregivers fail to acknowledge the agency of persons with IDD. In the same way as disablement is due at least in part to how society reacts to persons who appear to fall outside of what is considered "normal," so vulnerability is often caused, at least in part, by society's actions and attitudes towards certain members. Persons with IDD are at a particular risk to be rendered vulnerable because of the dominant understanding of freedom and agency. Thus, even those care givers who truly seek to encounter and be with persons with IDD may still be tempted to relate to them from a paternalistic stance, instead of truly respecting their freedom and appreciating and supporting their agency.

In contemporary ethics, freedom and moral agency are understood often in terms of an individual's autonomy and self-determination. To be autonomous or self-determining, an individual has to have the rational capacity to choose from among various options without

² Jean Vanier addressed the participants to the 2013 colloquium of the International Association of Catholic Bioethicists in a videotaped message. Hans Reinders personally attended the colloquium as a keynote speaker. Condensed videos of their presentations will be made available, pending permission of the authors, on the IACB website at <http://www.iacb.eu>.

³ The thoughts outlined subsequently in this paragraph are based in part on a presentation by Franziskus von Heereman during the 2013 colloquium of the International Association of Catholic Bioethicists. A condensed recorded video of his presentation will be made available, pending permission of the author, on the IACB website at <http://www.iacb.eu>.

⁴ Details of the elements of this ethical framework are elaborated in the colloquium's consensus statement. They are principles such as respect for the intrinsic dignity and worth of people with intellectual and developmental disabilities, being attentive to the uniqueness of each individual, taking into account the unity and integrity of the whole person, strengthening and fostering the conditions for meaningful relationships, supporting moral agency according to the person's capacities, attending to the needs of families, having a particular concern for the most needy and vulnerable, and offering solidarity to individuals and their families in their experiences of limitation and suffering.

interference from or dependence on psycho-affective or external determinants. Framed in these terms, an individual's freedom and the exercise of his or her moral agency is always considered in relation to unimpaired and unconstrained intellectual functioning and independence, and in opposition to the interests and demands of other people, which could restrict or curtail that individual's freedom. Such an understanding of freedom precludes moral agency in people with IDD to the extent that they have intellectual impairments and depend for their choices to varying degrees on the communities in which they live.

But what if we conceive of freedom and moral agency in a different way, as the capacity to apprehend values and to be supported in attaining them? Then people with IDD might not necessarily be precluded, or precluded entirely, from enjoying moral agency. We submit that people with IDD can be moral agents in so far as they are motivated in their decisions to act (or refrain from acting) by apprehensions of values, that is, universal and transcendent goods such as beauty, generosity, love, and the sheer joy of existing. These apprehensions of values are more than instinctive reactions of satisfaction or dissatisfaction. People with IDD might be capable of apprehending value even though they have limitations in conceptualizing and communicating what they apprehend. Even those with profound limitations have a capacity to receive and appreciate loving attention and care, and enjoy the simple and ordinary experiences of life, as goods and not merely as satisfying stimuli. Thus, such apprehensions do not depend on advanced intellectual functioning but are mediated through feeling and spiritual insight. In contrast, people who are excessively or unduly preoccupied with applying intelligence to be very productive or to attain social esteem can fail to apprehend these goods.

The implications of this understanding of freedom and moral agency for health care providers are significant: ethical care entails encountering and getting to know persons with IDD and their world so as to attain an adequate sense of their apprehensions of values. Even when some of them are assessed not to meet the legal standard for the capacity to give informed consent for decisions regarding their health care, they might have other capacities, such the ability to apprehend value, that enable them to participate in the decision-making process in a manner that is meaningful both to themselves and to their care givers. The support of family members and other regular caregivers to participate in decision making (e.g., by helping to interpret and communicate the person's apprehensions of values or making substitute decisions based on knowledge of those values when the individual lacks the legal requirements for informed consent) promotes and enhances the individual's freedom and moral agency, and does not detract from them.

It is important not to downplay the reality that individuals with IDD sometimes find themselves in tension or even conflict with the communities to which they belong because of certain behaviors they exhibit or decisions they make. When they are also legally able to consent to health care treatments, and hence refuse them too, these conflicts can be further exacerbated. The common response of health care professionals to only focus on the disruptive behaviors and refusals obscures the underlying causes and frustrates a constructive resolution. There is no authentic freedom for people with IDD if their behaviors and decisions undermine or harm the communities in which they are lovingly supported and cared for, and that enable their own particular form of agency. Yet these tensions and conflicts can usually be addressed within the context of a supportive

community by attentive communication with the individual that is adapted to his or her level of functioning and that seeks to uncover values that the person apprehends and affirms as meaningful. One of those values that can often motivate a constructive resolution is the value of being with and belonging. Persons with IDD tend to be deeply committed to the community in which they feel welcomed and loved, and eager to sustain and protect that community.

Conclusion

Our attempts to develop a comprehensive ethical framework for health care of people IDD and their families have led us to emphasize that:

- The disabilities suffered by persons with IDD are partly the result of the way in which society chooses to interact with them and shapes the environment in which they are expected to live; thus the lives of people with IDD can often be improved considerably by normalizing these contexts and fostering positive attitudes towards them as well as meaningful relationships with them.
- At the same time, it is important not to disregard the particular health needs of persons with IDD. A thorough understanding of the genetic and other biological causes of IDD can facilitate targeted and effective medical interventions, provided care givers do not fail to embed these treatments into holistic and community-based care plans.
- However, neither of the aforementioned two approaches adequately accounts for the intrinsic dignity of each individual human being, irrespective of his or her particular (dis)abilities. A focus on the fundamental and inalienable rights of all human beings goes a long way to rectify that shortcoming.
- But even this approach, because it emphasizes what all human beings have in common, fails to do justice to the uniqueness of each human being, including each person with IDD. Nor does it adequately recognize the crucial role that meaningful and loving relationships, which are not the same as entitlements, have in supporting people with IDD. By incorporating into the ethical framework concepts from Christian anthropology, health care providers can be encouraged to encounter people with IDD as unique individuals, each with their own particular calling and talents, and to promote conditions in the lives of people with IDD for developing friendships and other meaningful relationships.
- In all of this, it is crucial that concern for the vulnerability of persons with IDD does not lead health care providers paternalistically to do things for or to them only. Instead, health care providers must seek first and foremost to be with them, respecting their own freedom and agency. Particularly for persons with severe forms of IDD, this responsibility will challenge health care providers to think differently about agency. Rather than defining agency in terms of rational self-determination only, health care providers must remain mindful that agency also presents itself in the apprehension of universal and transcendent goods such as beauty, generosity, love, and the sheer joy of existing. By gaining insight into the particular values that

motivate their patients, health care providers will be able to develop care plans that are truly respectful of the uniqueness of each individual person with IDD.

- Finally, none of this can be realized effectively without considering the community of which persons with IDD are part. All human beings are communal beings but persons with IDD depend to an even greater degree on the community of which they are part for the realization of their life's goals and the attainment of well-being.

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