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**Caring for Persons with Intellectual and  
Developmental Disabilities**

**Ethical and Religious Perspectives**

Edited by Jos V. M. Welie

**Introduction**

**The Search for an Ethically Sound Approach to Caring for Persons with  
Intellectual and Developmental Disabilities**

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**Abstract**

The health care for persons with a developmental or intellectual disability (IDD) has greatly improved in recent decades, such that they live longer and enjoy better health. Paradoxically, eugenic efforts to prevent persons with IDD from even being born, marginalization of members with IDD from our communities, and extensive health care disparities persist as well. These concerns provided the impetus for the International Association of Catholic Bioethicists to devote its sixth bi-annual international colloquium (Rome, 2013) to an ethical

reflection on the care of persons with IDD. Reworked versions of several of the papers prepared for and presented at the colloquium were combined to create a JRS Supplement. In this introduction to the volume, the authors briefly present the main themes covered and conclude that the ethical insights gained merit the attention not only of those who are engaged in health care of persons with IDD, but of care givers of all patients.

Keywords: developmental disability, discrimination, ethics, health care, intellectual disability, personhood

## The Plight of Persons with IDD

In recent decades, humanity has come a long way in respecting the rights of the disabled, as evidenced by the 2006 adoption by the United Nations of the *Convention of Rights of People with Disabilities*. Likewise, many countries have adopted laws and policies that are intended to safeguard the fundamental rights of disabled members of our communities. But the very adoption of these important legal frameworks also signals that there is apparently a need for them, that disabled persons are still being discriminated against, marginalized, or even excluded from their communities. Clearly, there is a lot of work yet to be done to change hearts and minds.

What is true of society's general response to its members who are disabled, is true as well for the more specific area of health care. Nowadays, people with disabilities, particularly in the developed world, have much better access to the same high quality health care services to which all members of society have access, and as a result they live longer and enjoy better health. At the same time, recent studies have shown that many persons with disabilities are still not receiving health care of comparable quality that addresses their specific needs, resulting in delayed diagnoses, inadequate treatments, and even premature death. Elsewhere in this volume, Lennox, McPherson, and Van Dooren provide a detailed account of these shortcomings in our health care systems.

It has been said that the moral quality of any society hinges on the degree to which it cares for its most vulnerable members. What is true of civil society in general applies *a fortiori* to any community that claims to be guided by Christian moral principles. For as Christ had already made patently clear, anything done to the least in society is done to Christ himself (Matthew 25:40). The history of Christianity, unfortunately, contains too many examples of maltreatment of persons with disabilities, and in particular of persons with intellectual or developmental disabilities (IDD).<sup>1</sup>

Welie's paper in this volume is motivated by the nagging suspicion that the increased respect of persons with disabilities alluded to above does not apply equally to all types of disabilities. For sure, people with physical disabilities still face much discrimination, but the plight of people with IDD appears to be worse yet. Welie contends that this persistent devaluation of persons with IDD is due to our understanding of the nature of being human.

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<sup>1</sup> For the purposes of the Colloquium, the definition of IDD provided by the American Association on Intellectual and Developmental Disabilities was adopted: Intellectual and developmental disabilities are lifelong challenges to cognitive, adaptive and social skills that result from differences in neuropsychological development before adulthood.

The Platonic identification of personhood with rationality, which has unfortunately persisted into our contemporary culture, puts individuals with IDD, and specifically those with severe forms of IDD, at risk of being regarded as incomplete persons or even as non-persons. Within a Christian frame of reference, physical disability is compatible with being created in the image of God. After all, Christ was severely tortured and utterly disabled while dying on the cross, an event completely incompatible with ancient Greek and Roman understandings of divinity. But Welie speculates that the idea of an intellectually or developmentally disabled God is much harder to accept, even for Christians who remain influenced by neoplatonic theology, which can then cast doubt on the conviction that persons with IDD are holy as well, and hence deserve the same respect as those who have a physical disability or no disability.

### **Towards a New Ethical Framework**

These types of concerns provided the impetus for the International Association of Catholic Bioethicists (IACB) to devote its sixth bi-annual international colloquium to the topic of “Supporting and Caring for Persons with Intellectual and Developmental Disabilities” (Villa Palazzola, Rome, Italy, June 9-14, 2013). The IACB functions under the auspices of the Order of Malta, founded at the end of the eleventh century as one of the hospitaller orders. The Order of Malta has itself a long history of providing health care to vulnerable and marginalized populations in societies around the world. The 2013 colloquium in Rome was attended by 64 scholars, health professionals, and other care providers, representing 16 countries. The principal objective of the colloquium was the development of a new ethical framework for health care of people with IDD. The Consensus Statement that emerged out of that meeting has been included in this Supplement of the *Journal of Religion & Society* as the final contribution. The scholarly papers collected in this volume are the result of research undertaken in preparation of presentations at the colloquium,<sup>2</sup> feedback from and discussion with participants, and subsequent reflection and refinement. Hoping to inspire further discussion and reflection, the authors would welcome additional feedback and contact information for each author is available below.

Of grave concern to those who care for persons with IDD is the persistent willingness of many in society to curb the prevalence of IDD by eliminating persons with IDD. In his opening remarks to the Rome colloquium, Frà Matthew Festing, Grand Master the Order of Malta, recalled his long experience ministering to pilgrims, and therefore also disabled pilgrims, and regretted the change for the worse that he had noticed over the years as a result of eugenic abortions with ever fewer disabled persons being among the arriving pilgrims.<sup>3</sup> Von Boeselager, then Grand Hospitaller and current Grand Chancellor of the Order of Malta, reminded the audience that as recent as 2009, the European Parliament discussed a Commission proposal on the elimination of rare genetic diseases. Notwithstanding the

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<sup>2</sup> The one exception is the paper by Babcock and Welie, which was not presented at the conference but added to this volume because of the thematic fit.

<sup>3</sup> The recording of the address by Frà Festing, as well as condensed recordings of most other presentations given at the 2013 colloquium, pending permission, will become accessible through the website of the IACB at <http://www.iacb.eu/>.

euphemistic terminology used in the proposal, one of the means of elimination it explicitly proposed in Amendment 15 was the pre-implantation selection of healthy human embryos to prevent the further spread of the disease. In her translation of the debate, the German interpreter used the phrase “*Vernichtung lebensunwerten Lebens*” – the extermination of life not worthy of being lived – which is exactly the same phrase that was used by the Nazi regime to denote the killing of mentally sick and disabled persons. Amendment 15 was critiqued by many parliamentarians, but the report was ultimately accepted by majority vote as amended.<sup>4</sup> Though the European Commission did not next implement this part of the report, the event underscores the persistence of eugenic attitudes in the twenty-first century, which is the main theme of the contribution to this volume by von Ritter.

But most authors who are concerned about discriminatory disrespect towards persons with IDD grant that the condition of IDD itself merits prevention and treatment. Indeed, the aforementioned United Nations convention prohibits discrimination against persons with IDD while at the same time calling for adequate care provisions to meet the specific needs of such individuals and their families. In short, disabilities should not be considered and yet be specifically considered when providing health care services. This dual, even paradoxical challenge by the United Nations underscores the need for a new and robust normative framework that can guide health care providers and other care givers of persons with IDD.

In their contribution, Sullivan and Heng lay the groundwork for such a framework by critically reviewing several models of care currently in use. They rely on the important contributions by Jean Vanier, the founder of the international L’Arche communities, who challenged the Rome colloquium participants in a videotaped address to reflect on and discuss what an ethics of “being with” people with IDD would look like in health care. To be sure, “being with” is not the same as “being inclusive.” Peter Comensoli, Bishop of Broken Bay, Australia, warns in his contribution to this volume that best intentions notwithstanding, the quest by advocates for people with disabilities to foster inclusion misses the most important point. Such inclusive attempts presume that people with disabilities are on the outside and that it is within the power of those on the inside to include them. This, then, perpetuates their status as outsiders whose belonging to the human community is not inherent but dependent on the generosity of the powerful. Referencing Vanier, Comensoli calls upon the powerful not to “pull up” the disabled out of their supposedly lowly predicament but instead to let go of their own claim to power and join the disabled exactly where they are living out their particular way of being human.

This is also the main theme of the unique contribution to this volume by colloquium speaker Kareem Elbard, a 38 year old gentleman who has IDD. He challenges caregivers who are non-disabled, and hence not personally familiar with the condition of IDD, to bracket their usual habit of imposing norms and valuations onto persons with IDD, and let the experiences and insights of persons with IDD guide them instead. Now, this is relatively easy to accomplish in the case of individuals such as Elbard who is a most eloquent and

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<sup>4</sup> See the text of the Commission proposal, as amended and adopted by the European Parliament (2009a) and the minutes of the parliamentary debate (2009b).

persuasive advocate of the interests of persons with IDD. But some persons with IDD communicate in a language that is much harder to understand. Bradley, Caldwell, and Korossy in their paper remind us that persons with profound IDD may communicate by means of behaviors rather than words. Moreover, the behaviors they exhibit can differ from what health care providers may be familiar with based on traditional psychiatric diagnostic frameworks. If we fail to learn the unique body language of persons with IDD, our clinical treatments are likely to fail and we may even end up unintentionally harming them.

Learning their language thus is a necessary condition for providing beneficial care; but it may not be a sufficient condition. More generally, respect of the intrinsic dignity, uniqueness and freedom of persons with IDD does not always suffice to ensure their well-being is attended to adequately, particularly if the IDD is more severe. An area where this dilemma manifests itself very clearly is the area of human sexuality. As all human beings, persons with IDD are sexual beings who long for love and physical closeness. But they may not be able to effectively assume all of the responsibilities that accompany sexual engagement, and they are themselves at great risk of being sexually abused. In their paper, Jamieson and Markwell examine the appropriate balance between promoting participation, independence, and capacity for self-determination of adults with IDD on the one hand, and on the other hand paternalistically protecting them from imprudent lifestyles and engagements that may be harmful to them or others in their communities.

Jamieson and Markwell suggest that the notion of a “duty to care,” which has been effectively used in ethical decision making when public health emergencies engender conflicts among competing interests and claims, can also be helpful in sorting through these ethical dilemmas. Babcock and Welie in their contribution tackle the same dilemma between respecting freedom of persons with IDD and paternalistically protecting their well-being, but they interrogate the concept of paternalism instead. In the bioethical literature, paternalism towards adult patients is generally viewed as disrespectful and rarely if ever justifiable. But such a blanket rejection of paternalism in the relationship between persons with IDD and their caregivers seems untenable and indeed harmful to all involved. Rather than focusing on health care decision making, Babcock and Welie examine the conditions under which paternalistic care is justifiable in reference to the promotion of spiritual well-being of persons with IDD. They conclude that paternalistic inclusion in communal spiritual practices may actually foster personal growth and individual self-determination for people with IDD because empathy and relationality, rather than rationality and autonomy, are primary modes of perceiving the world and their place within it.

### **An Ongoing Search**

The papers included in this volume do not provide a comprehensive, let alone definitive answer to the search for an ethically sound approach to the care of persons with IDD. The many tensions, dilemmas, and even paradoxes that are discussed in this volume underscore that deep seated preconceptions and prevalent biases render this search a real struggle, even for health care professionals and ethics scholars who simply take for granted that all persons with IDD, whether at an embryonic age, adult, or terminally ill, and regardless the nature and severity of their disability, are created in God’s image and, as all other members of the human community, are on their own journey back to God.

Then again, maybe this struggle is as it should be. Maybe it is our everyday bioethical discussion about the health care of patients in the general population that is too perfunctory and unduly straightforward. Our being with, and reflections on the care of persons with IDD show that the analytical toolbox of contemporary bioethics is woefully inadequate. It not only fails to account for the particular journeys of persons with IDD, but ultimately forces upon all of us an understanding of being human that provides rather poor guidance in our own journeys back to God.

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