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

**Ethical and Religious Perspectives**

Edited by Jos V. M. Welie

**People with Intellectual and Developmental Disabilities  
and Their Families**

**An Ethical Framework and Recommendations for Health Care Practices  
and Policies**

**Consensus Statement of the 6<sup>th</sup> International Colloquium of the  
International Association of Catholic Bioethicists (IACB)<sup>1</sup>**

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<sup>1</sup> Although William F. Sullivan and John Heng are the authors of this statement, the content is based on discussions held during the 6<sup>th</sup> International Colloquium of the IACB, July 9-14, 2013, as well as on subsequent comments and editorial suggestions offered by various participants in the Colloquium.

*JRS Editor's Note:* The consensus statement has been reprinted here verbatim, without modification to fit the journal's style. The consensus statement is published concurrently in the *National Catholic Bioethics Quarterly*.

## Introduction

This statement summarizes the principal findings of participants in the 6<sup>th</sup> International Colloquium of the International Association of Catholic Bioethicists (IACB) held in Rome, Italy, June 9-14, 2013. The ethical framework and recommendations presented here are based on the presentations and discussions at the colloquium and represent the consensus of the signatories who are listed at the end of this statement. The statement indicates in footnotes some points that were left as questions for further research, reflection and discussion.

### a. Understanding the topic

*What are intellectual and developmental disabilities?*

Intellectual and developmental disabilities are lifelong challenges to cognitive, adaptive and social skills that result from differences in neuropsychological development before adulthood. These challenges vary in type and severity from individual to individual.<sup>2</sup>

It should be noted that different diagnostic criteria and terminology are applied around the world for intellectual and developmental disabilities, and these change over time. The use of the term *intellectual and developmental disabilities* in this statement overlaps in meaning with other terms that might be encountered elsewhere, such as *intellectual disability*, *developmental disabilities*, *intellectual developmental disorder*, *learning disability*, *developmental delay*, and *mental handicap*.<sup>3</sup>

In this statement, the term *intellectual and developmental disabilities* also includes *Autism Spectrum Disorder*. Although some individuals with an Autism Spectrum Disorder do not meet cognitive and language impairment criteria for intellectual and developmental disabilities, they have impaired adaptive and social abilities. They share many similar challenges in health and health care as people with cognitive and language impairments.

*Causes of intellectual and developmental disabilities*

Most intellectual and developmental disabilities do not have a known cause.<sup>4</sup> For some, a genetic basis has been identified (e.g., Down syndrome and Fragile X syndrome). Others

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<sup>2</sup>Schalock RL, Borthwick-Duffy S, Bradley VJ, et al., *Intellectual disability: definition, classification, and systems of supports*. 11th ed. Washington, DC: American Association on Intellectual and Developmental Disabilities; 2010. The AAIDD's definition of *intellectual disability* is based on adaptive skills and is the most widely used definition internationally for what we refer to here as *intellectual and developmental disabilities*.

<sup>3</sup> Another term *mental retardation* was prevalent in the past but is now less used and generally avoided because it has acquired a pejorative connotation.

<sup>4</sup> Percy M. Factors that cause or contribute to intellectual and developmental disabilities. In Brown I, Percy M, eds. *A comprehensive guide to intellectual and developmental disabilities*. Boston: Paul H. Brookes Publishing, 2007, 125-148.

have been linked to environmental, prenatal or perinatal factors (e.g., Fetal Alcohol Spectrum Disorder and some instances of Cerebral Palsy). Still others appear to have multiple causes (e.g., Autism Spectrum Disorder).

*People with intellectual and developmental disabilities*

People with intellectual and developmental disabilities are members of the human family. They are present throughout the world and generally comprise between one and three percent of any country's population. Given the world's unequal wealth distribution, this means that most are found in resource-poor countries, which compounds the challenges they already face. In developed countries, fewer people with intellectual and developmental disabilities than in the past reside in institutions that are separate from the rest of the community. Many live with their families. Some adults live in group homes or on their own. Others reside in long-term care facilities for people with chronic and/or mental illness or in prisons where they often do not have appropriate health care and supports. Another disturbing reality in many parts of the world is the growing number of people with intellectual and developmental disabilities who are homeless and left to fend for themselves.<sup>5</sup>

Historically people with intellectual and developmental disabilities have been poorly understood, devalued and excluded in society. Even if they live in their communities, they might still experience the negative attitudes of other people, ridicule, discrimination and isolation. People with intellectual and developmental disabilities are seldom consulted regarding decisions that affect their lives. Many live in poverty. Neglect, abuse and trauma are prevalent among people with intellectual and developmental disabilities.<sup>6</sup> The combination of these factors has a cascading effect that can increase the severity and complexity of the challenges that they face in health and health care.<sup>7</sup>

Acceptance and inclusion can improve the lives of people with intellectual and developmental disabilities, their family members and others who are their primary caregivers. When accepted and included in society, they have opportunities to develop friendships and other meaningful social relationships, as well as receive appropriate education, care and supports. Those who live and work with people with intellectual and developmental disabilities attest that, when we accept and include them, they can enrich our world and teach us the core of what it means to be human.<sup>8</sup>

*Health care of people with intellectual and developmental disabilities*

Health is a basic and significant contributor to the well being of people with intellectual and developmental disabilities and to their inclusion and participation in society. The United

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<sup>5</sup> Mercier C, Picard S. Intellectual disabilities and homelessness. *Journal of Intellectual Disabilities Research* April 2011; 55(4): 441-449.

<sup>6</sup> Horner-Johnson W, Drum CE. Prevalence of maltreatment of people with intellectual disabilities: a review of recently published research. *Mental Retardation and Developmental Disabilities Research Reviews* 2006; 12(1): 57-69.

<sup>7</sup> Krahn GL, Hammond L, Turner A. A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews* 2006; 12(1): 70-82.

<sup>8</sup> Jean Vanier, *Becoming human*. Toronto: House of Anansi Press, 1968, pp. 6, 45.

Nations' *Convention on the Rights of Persons with Disabilities* declares that "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability."<sup>9</sup> It asserts that they have a right to health care services "specifically because of their disability". It urges health care professionals to provide "care of the same quality to persons with disabilities as to others". Studies have shown, however, that even in relatively resource-rich countries such as Australia, Canada, European countries and the United States, people with intellectual and developmental disabilities as a group receive inadequate or inappropriate health care.<sup>10</sup> They often cannot access health care services and preventive care programs that are available and offered to the general population. They also have difficulty receiving care appropriate to the particular nature of their disabilities.<sup>11</sup>

Illnesses and other health disorders in people with intellectual and developmental disabilities might differ from those encountered in the general population in prevalence, age of onset, rate of progression, degree of severity, and presenting manifestations.<sup>12</sup> Training of health care providers is crucial to recognizing and understanding the particular health issues of people with intellectual and developmental disabilities. Adaptations in health care practices are often required to communicate with people with intellectual and developmental disabilities, assess and support their capacity to make informed decisions, and enhance their comfort, safety and care. In only a few countries, however, are practice guidelines and resources available to train health care professionals specifically to care for such people. Moreover interdisciplinary collaboration and continuity of care throughout life, which must be well coordinated to address the complex health issues of people with intellectual and developmental disabilities effectively, are not always available to them.

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<sup>9</sup> United Nations. *Convention on the rights of persons with disabilities*. New York, NY: United Nations, 2006. Article 25. While the Holy See supported the main thrust of this Convention to defend the dignity and rights of persons with disabilities, it did not ratify this Convention because of wording regarding "reproductive health services" that in some countries include the possibility of aborting a child that has been diagnosed with the likelihood of having a disability. In his speech to the United Nations, the Permanent Observer of the Holy See at the time of the Convention's adoption remarked, "It is surely tragic that, wherever fetal defect is a precondition for offering or employing abortion, the same Convention created to protect persons with disabilities from all discrimination in the exercise of their rights, may be used to deny the very basic right to life of disabled unborn persons." See [http://www.vatican.va/roman\\_curia/secretariat\\_state/2006/documents/rc\\_seg-st\\_20061213\\_un-rights-persons\\_en.html](http://www.vatican.va/roman_curia/secretariat_state/2006/documents/rc_seg-st_20061213_un-rights-persons_en.html)

<sup>10</sup> Scheepers M, Kerr M, O'Hara D, et al. Reducing health disparity in people with intellectual disabilities: A report from Health Issues Special Interest Group of the International Association for the Scientific Study of Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities* 2005; 2(3-4): 249-255.

<sup>11</sup> For example, the report of an inquiry into 247 deaths between 2010 and 2012 of people with intellectual and developmental disabilities registered with the National Health Service in England concluded that 37% of those deaths could have been avoided with more timely or more appropriate health care or service provision. This was three times the rate of avoidable deaths of individuals without intellectual and developmental disabilities, matched by age, sex, and similar causes of death. Heslop P, Blair PS, Fleming P, et al. The confidential inquiry into premature deaths of people with intellectual disabilities in the U.K.: a population-based study. *Lancet* 2014 Mar 8; 383(9920): 889-95.

<sup>12</sup> Sullivan WF, Berg JM, Bradley E, et al. Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Canadian Family Physician* May 2011; 57(5): 541-553, on 544.

**b. Aim and focus of this consensus statement**

The aim of this consensus statement is to propose an ethical framework for making decisions regarding the health care of people with intellectual and developmental disabilities and the family members and others who are their primary caregivers. Based on this framework, the statement offers some specific recommendations regarding health care practices and policies.

This statement goes beyond the legal framework of the United Nations' *Convention on the Rights of Persons with Disabilities*. It strongly affirms the Convention's emphasis on upholding the human rights of people with disabilities and promoting their inclusion in society, but does so from ethical and theological foundations that prioritize the personal, relational and spiritual dimensions of inclusion. Above all, this statement highlights the importance of health care providers *being with* people with intellectual and developmental disabilities, their families and other loved ones, and not simply on *doing things to or for* them.

**c. To whom is this statement addressed?**

This statement addresses mainly those involved in the health care of people with intellectual and developmental disabilities, including the related areas of research, teaching, spiritual and pastoral care, administration, law and policy development. It also contains ethical considerations and recommendations relevant to family members and others who are the primary caregivers of people with intellectual and developmental disabilities, as well as to government and religious leaders.

The statement addresses both Catholics and non-Catholics. It is informed by Catholic teaching and theological reflection, but draws upon many principles that are held in common by other Christians and non-Christian faith traditions. It is based also on philosophical and ethical reasoning that can be considered and discussed by people who do not adhere to any faith tradition.

**d. Organization of the Colloquium by the IACB**

The IACB was founded in 2005. Its main activity is organizing international and regional colloquia to enable bioethicists and health care professionals to discuss overlooked, emerging and controversial ethical issues. The IACB's twofold purpose is to enhance the capacity of Catholics to engage in public discussions on bioethical issues for the common good and to help advance the thinking of Catholics in those areas of bioethics where Church teaching has not yet been developed or where there are divergent applications of such teaching. IACB colloquia have been held in Toronto, Melbourne, London, Paris, Cologne, Philadelphia, Madrid and Rome. The discussions during the IACB international colloquia are summarized in various consensus statements, which have been published in the *National Catholic Bioethics Quarterly* and made available online at the IACB website<sup>13</sup>. Previous such statements address the topics of care of the frail elderly<sup>14</sup>, medically assisted nutrition and

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<sup>13</sup> <http://www.iacb.eu>

<sup>14</sup> *National Catholic Bioethics Quarterly* 2004; 4(1): 151-58.

hydration<sup>15</sup>, respect for human dignity in health care systems that have appropriated business models of administration and management<sup>16</sup>, stem cell research and regenerative medicine<sup>17</sup>, the care of people with Alzheimer disease and related progressive cognitive impairments<sup>18</sup>, and the use of sedatives in the care of persons who are seriously ill or dying<sup>19</sup>.

#### e. Sponsorship of the IACB

The IACB operates under the auspices of associations of the Order of Malta. The Order is a 900-year-old international humanitarian organization whose mission is to witness to the Catholic faith and devotedly serve the poor (“*tuitio fidei et obsequium pauperum*”), including people who are sick and those with disabilities. The Order’s mission is supported and promoted by the IACB’s work in bioethics. The associations of the Order, in turn, provide financial, moral and spiritual support to the IACB. They sponsor the IACB’s colloquia while respecting the openness of inquiry and discussions that characterize these colloquia. The 6<sup>th</sup> International IACB Colloquium was co-sponsored by the Order of Malta’s Canadian and Italian Associations, the Grand Priory of Rome, and the Order’s governing body, the Grand Magistracy, in celebration of the Order’s 900<sup>th</sup> anniversary.

#### f. Process of the colloquium

The 6<sup>th</sup> International Colloquium of the IACB brought together sixty-four participants who were identified and invited by an international committee of experts on the health care of people with intellectual and developmental disabilities. The participants were selected because of their knowledge and experience in bioethics or intellectual and developmental disabilities. The participants had diverse backgrounds. They came from Asia, Europe, Oceania, North and South America. They included an adult with intellectual and developmental disabilities and his mother who each gave presentations and participated in all the activities of the colloquium, as well as several family members of other people with intellectual and developmental disabilities. Also participating were some teachers and support workers of people with intellectual and developmental disabilities.

Other participants in the colloquium included neuroscientists, practitioners in various health sciences (obstetrics, pediatrics, family medicine, public health, psychiatry, oncology, nursing, speech-language pathology, physical therapy, and occupational therapy), and academics with expertise in sociology, philosophy, theology, law, canon law, health care ethics, social work, disability studies and thanatology. Among the participants were several members of the clergy and providers of spiritual and pastoral care from Catholic and Protestant traditions, directors and staff members of Catholic diocesan offices. Some participants were not affiliated with any faith tradition. The main sessions of the colloquium

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<sup>15</sup> *National Catholic Bioethics Quarterly* 2004; 4(4): 773-82.

<sup>16</sup> *National Catholic Bioethics Quarterly* 2005; 5(4): 767-81.

<sup>17</sup> *National Catholic Bioethics Quarterly* 2008; 8(2): 322-39.

<sup>18</sup> *National Catholic Bioethics Quarterly* 2010; 10(3): 549-67.

<sup>19</sup> *National Catholic Bioethics Quarterly* 2012; 12(3): 489-501.

were shared through live webcasting with individuals who could not attend in person but were able to participate from a distance by submitting comments and questions online.

There were seven papers commissioned for the colloquium, which participants read in advance of the colloquium. The authors of these papers presented their main points at the colloquium. In addition to these presentations, thirteen participants in the colloquium were invited to offer responses to the commissioned papers and short communications on related topics. The commissioned papers were written and presented by Franziskus von Heereman (Germany), Jos Welie (U.S.A.), Hans Reinders (Netherlands), Nicholas Lennox (Australia), Anthony Holland and Dieuwertje de Waardt-Morsink (U.K. and Netherlands, respectively), Cristina Gangemi and Pia Matthews (U.K.), and John Keown (U.S.A.). Responses and communications were presented by Albrecht von Boeselager (Germany), William F. Sullivan (Canada), Bishop Peter Comensoli (Australia), Sarah Buckley (Australia), Ian Casson and Meg Gemmell (Canada), Pamela Cushing (Canada), Elizabeth O'Brien (U.K.), Christine Jamieson and Hazel Markwell (Canada), Fr. Joseph Chandrakanthan (Canada), Christoph von Ritter (Germany), Elspeth Bradley (Canada), Kareem and Heather Elbard (Canada) and Marcia Riordan (Australia).

Discussion in small groups of participants followed each set of presentations. Group facilitators and recorders were Fr. Gerry Gleeson and Bernadette Tobin (Australia), Paulina Taboada (Chile), Jaro Kotalik (Canada), Fr. Paul Chummar (Germany), Moira McQueen (Canada), Linda Scheirton (U.S.A.) and Luigi Castagna (Canada). In plenary sessions, these facilitators and recorders presented the most important points and questions that arose during the small-group sessions for further discussion. William F. Sullivan and John Heng (Canada) then prepared drafts of the consensus statement. Participants reviewed and discussed these drafts during the final day of the colloquium and also submitted written comments before leaving. From this feedback, a third draft of the consensus statement was prepared after the colloquium and circulated for comment and suggestions for editing. All participants in the 6<sup>th</sup> International IACB Colloquium were invited to be signatories of the final version of this statement.

#### **g. Communication of the results of the colloquium**

The results of the 6<sup>th</sup> IACB International Colloquium will be shared in various ways: This consensus statement is being published concurrently in the *Journal of Religion & Society* and the *National Catholic Bioethics Quarterly*. In addition to this consensus statement, many of the papers and communications presented at the colloquium will also be published in a special issue of the peer-reviewed, open-access, online *Journal of Religion & Society*.<sup>20</sup> The presentations at the colloquium were videotaped, and abbreviated versions of these videos, with the approval of the presenters, will be publicly available on the IACB website. Finally, a summary of the consensus statement will be prepared with and for people with intellectual and developmental disabilities and included on the IACB website.

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<sup>20</sup> <http://www.creighton.edu/jrs/>

## Consensus Statement

### Ethical framework

The participants in the 6<sup>th</sup> International Colloquium of the International Association of Catholic Bioethicists (IACB) held in Rome, Italy, from June 9-14, 2013, endorsed the following ethical framework. Applying these general foundational principles to make decisions regarding care of people with intellectual and developmental disabilities will involve prudential judgments that should take into consideration both the concrete lived experiences of such people, their family members and others who are their primary care givers, as well as the accumulated wisdom of those who have experience making these sorts of decisions. It is crucial, therefore, to get to know the people who are affected by the decision and to make these decisions in dialogue with them, and also to consult members of the community who are knowledgeable about people with intellectual and developmental disabilities.

### Principles

#### A. Respect the intrinsic dignity and worth of persons with intellectual and developmental disabilities

1. 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.<sup>21</sup> The position that it is ethically acceptable to suspend the rights of some human beings when this serves the good of the majority in a group should also be rejected.<sup>22</sup> The United Nations' *Universal Declaration of Human Rights* affirms that "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world."<sup>23</sup>
2. Christian teaching affirms the intrinsic dignity and equal worth of all human beings. For Christians, every human being is made in the image and likeness of God.<sup>24</sup> Each human being, without exception, is known and immeasurably loved by God.<sup>25</sup> 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. The Second Vatican Council's Pastoral

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<sup>21</sup> This is the position, for example, of some thinkers like Peter Singer, who argue 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. See Singer, P. *Practical ethics*. Cambridge: Cambridge University Press, 1979, especially pp. 76-84. For more philosophical elaborations of the account of the worth of human beings assumed in this statement, see MacIntyre, A. *Dependent rational animals: why human beings need the virtues*. Chicago: Open Court, 1999, and Jones DA. Incapacity and personhood: Respecting the non-autonomous self, in *Incapacity and Care: Controversies in Healthcare and Research*, Watt D., ed. Oxford, U.K.: The Linacre Centre (Anscombe Bioethics Centre), 2009.

<sup>22</sup> For example, this is the position advanced by some proponents of utilitarianism in ethics.

<sup>23</sup> United Nations. *Universal declaration of human rights*. New York, NY: United Nations, 1948. Preamble.

<sup>24</sup> Genesis 1: 26-27.

<sup>25</sup> Psalm 139.



Constitution of the Church in the World, *Gaudium et spes*, explains that “the root reason for human dignity lies in humanity’s call to communion with God.”<sup>26</sup>

3. The challenges that people with intellectual and developmental disabilities have in cognitive, adaptive or social skills do not alter the reality that they are human beings and belong to the human family. As such, they have inherent dignity and equal worth to other human beings. This entails various ethical duties in health care, such as having genuine positive regard for people with intellectual and developmental disabilities, attending to their needs, concerns and distresses, supporting them in making decisions to the extent of their abilities, being an empathetic presence for them, and promoting their overall well being. It also entails not neglecting them, not discriminating against them, and not harming them. Health care providers should not regard people with intellectual and developmental disabilities as “defective” and should not judge them as lacking a perspective worth considering or as having a life not worth living.

*B. Respect the uniqueness of each person with intellectual and developmental disabilities*

4. Human development is shaped by diverse factors. There is no “perfect” human genotype or phenotype but a range of variations. Each human being is unique. Every individual possesses a different combination of abilities and limitations that can change throughout life.
5. For Christians, every human being has an individual soul that is “created immediately by God-it is not ‘produced’ by the parents-and...is immortal.”<sup>27</sup> Each human being is a unique creation of God that God has deemed “good”.<sup>28</sup>
6. Appropriate health care addresses the particular, personal needs and concerns of individuals with intellectual and developmental disabilities. This entails encountering and getting to know each person who has his or her own personality, motivations, abilities, limitations, relationships, environments, life circumstances and experiences, and making appropriate decisions and adaptations in each case.

*C. Respect the unity and integrity of the whole person in people with intellectual and developmental disabilities*

7. Every human being consists of a manifold of material and spiritual aspects relating to one another. No human being is reducible to a part or function of his or her being.

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<sup>26</sup> *Pastoral constitution of the Church in the world (Gaudium et spes)*. Vatican Council II (Dec. 7, 1965), no. 19. Available online at: [http://www.vatican.va/archive/hist\\_councils/ii\\_vatican\\_council/documents/vat-ii\\_cons\\_19651207\\_gaudium-et-spes\\_en.html](http://www.vatican.va/archive/hist_councils/ii_vatican_council/documents/vat-ii_cons_19651207_gaudium-et-spes_en.html)

<sup>27</sup> *Catechism of the Catholic Church*, no. 366. English translation, 2<sup>nd</sup> ed. Washington, D.C., U.S.A: U.S. Catholic Conference of Catholic Bishops, 2000. Available online at: [http://www.vatican.va/archive/ENG0015/\\_INDEX.HTM](http://www.vatican.va/archive/ENG0015/_INDEX.HTM)

<sup>28</sup> Genesis 1:31.

Some writers in health care have articulated this principle in terms of a bio-psycho-social-spiritual model of the patient.<sup>29</sup>

8. For Christians, human beings are naturally oriented toward seeking ultimate meaning and have a desire for what transcends limited material reality because they have a spiritual soul, which forms with the body a single human nature.<sup>30</sup> Both bodily gestures and feelings can manifest these spiritual capacities in human beings. People with intellectual and developmental disabilities, even those with severe or profound disabilities, have these spiritual capacities.
9. Interdisciplinary and holistic health care can best address the needs of people with intellectual and developmental disabilities, their families and other loved ones. Such care should include attention to spiritual needs and offer spiritual and pastoral care.

*D. Strengthen and promote supportive human relationships that are essential to the well being of people with intellectual and developmental disabilities*

10. Human beings are inherently beings in relationships. They depend on one another, are nurtured by relationships, and have the capacity and desire to love and be loved.
11. 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.<sup>31</sup> Christian love or *caritas* does not depend 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. Emeritus Pope Benedict XVI has written of this Christian foundation for providing care to others: "Seeing with the eyes of Christ, I can give to others much more than their outward necessities; I can give them the look of love which they crave."<sup>32</sup>
12. Supportive relationships and communities can nurture people with intellectual and developmental disabilities throughout their lives. Such persons are able to receive love, care and support from others even if their capacity to reciprocate such love might be limited to some extent. For health care providers, family members and other direct caregivers, being with people with intellectual and developmental disabilities and being attentive to them can often lead to discovering and developing empathy, ethical responsibility and unconditional love.

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<sup>29</sup> Sulmasy DP. A biopsychosocial-spiritual model for the care of patients at the end of life. *Gerontologist* 2002 Oct; 42 Spec. No. 3: 24-33.

<sup>30</sup> *Catechism of the Catholic Church*, no. 365.

<sup>31</sup> *Pastoral constitution of the Church (Gaudium et spes)*. Vatican Council II (Dec. 7, 1965), no. 12: "For by his innermost nature man is a social being, and unless he relates himself to others he can neither live nor develop his potential." See also International Theological Commission, *Communion and stewardship: Human persons created in the image of God*, no. 42-43, and John Paul II, *Redemptor hominis* (1979), n.10.

<sup>32</sup> Benedict XVI, *Deus caritas est* (2005), no. 18. Available online at: [http://www.vatican.va/holy\\_father/benedict\\_xvi/encyclicals/documents/hf\\_ben-xvi\\_enc\\_20051225\\_deus-caritas-est\\_en.html](http://www.vatican.va/holy_father/benedict_xvi/encyclicals/documents/hf_ben-xvi_enc_20051225_deus-caritas-est_en.html).

*E. Support the moral agency of persons with intellectual and developmental disabilities to the extent of their abilities, taking into account their significant relationships*

13. A correct understanding of the principle of respect for autonomy or moral agency should always take into account the reality of human interdependency and the importance of an individual's supportive relationships and community. Respecting an individual's freedom and promoting the safety and well being of his or her community are not necessarily opposed principles. While no community can flourish unless it respects the freedom and moral agency of its individual members, the safety and well being of these individuals depend upon their supportive relationships and their living in and belonging to harmonious communities.
14. For Christians, human freedom is God's gift. It is properly understood, not as freedom *from* obligations and constraints imposed on a person by others, but as freedom *for* pursuing lasting goods that God has willed for human flourishing, including human relationships and community.
15. The tension between freedom and belonging, which is at the heart of all human relationships, is also experienced in being with people with intellectual and developmental disability and caring for them. The capacity of people with intellectual and developmental disabilities to make free and informed decisions regarding their personal care and other factors affecting it should be appropriately assessed, assisted when necessary by people who know these individuals well, and accommodated as much as possible by their families and communities. Assessing the decision-making capacity of these individuals, however, entails taking into account the degree to which they can understand and appreciate how their decision both affects themselves and the relationships on which they depend for their support and well being.

*F. Attend to the needs of families of people with intellectual and developmental disabilities*

16. For human beings, the first relationships are those within the family. The family is the basic unit of society. Social institutions and the state, therefore, ought to provide as much assistance as possible to enable families to flourish.
17. For Christians, the family is part of God's plan of creation as the "basis and beginning of all human society"<sup>33</sup>, an image of the triune God, and the "domestic church".<sup>34</sup> The principle of subsidiarity, drawn from the social teaching of the Catholic Church, proposes a relevant consideration regarding the relationship between the family and the state. *The Compendium of the Social Doctrine of the Church* explains that subsidiarity requires all societies at a higher level of organization to support, promote, and develop the

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<sup>33</sup> John Paul II, *Apostolic exhortation familiaris consortio* (November 22, 1981), no. 42. Available online at: [http://www.vatican.va/holy\\_father/john\\_paul\\_ii/apost\\_exhortations/documents/hf\\_jp-ii\\_exh\\_19811122\\_familiaris-consortio\\_en.html](http://www.vatican.va/holy_father/john_paul_ii/apost_exhortations/documents/hf_jp-ii_exh_19811122_familiaris-consortio_en.html)

<sup>34</sup> *Dogmatic constitution of the Church (Lumen gentium)*. Vatican Council II (Nov. 21, 1964), no. 11. Available online at: [http://www.vatican.va/archive/hist\\_councils/ii\\_vatican\\_council/documents/vat-ii\\_const\\_19641121\\_lumen-gentium\\_en.html](http://www.vatican.va/archive/hist_councils/ii_vatican_council/documents/vat-ii_const_19641121_lumen-gentium_en.html)

capacities of those at a lower level.<sup>35</sup> Thus “[i]n the conviction that the good of the family is an indispensable and essential value of the civil community, the public authorities must do everything possible to ensure that families have all those aids (economic, social, educational, political and cultural assistance) that they need in order to face all their responsibilities in a human way.”<sup>36</sup>

18. For people with intellectual and developmental disabilities, their family might include a broader range of individuals than members of their biological family. There should be a partnership between health care providers and the families of people with intellectual and developmental disabilities. It is often family members and other loved ones who are the primary caregivers of people with intellectual and developmental disabilities and who know them best. Families can contribute relevant and helpful information, perspectives and support for health care. Many families of people with intellectual and developmental disabilities, however, do not have sufficient or appropriate resources for caregiving, are worried about the present or future situation of their family member with intellectual and developmental disabilities, and experience stress in caregiving. Their needs and concerns should be attended to and addressed.

#### G. Promote social justice

19. An understanding of the common good entails special concern for disadvantaged and vulnerable people in society. A society treats its members equitably only if it also includes and provides the support that disadvantaged and vulnerable human beings need to participate and share in the goods that are available to all.
20. Catholic social teaching proposes that “the poor, the marginalized and in all cases those whose living conditions interfere with their proper growth should be the focus of particular concern.”<sup>37</sup> Christians seek to imitate Christ who, during his earthly life, reached out to and helped especially those who had ailments and disabilities and those least members of society who were shunned and marginalized. Regarding loving service of these persons, Christ told his disciples, “just as you did it to one of the least of these who are members of my family, you did it to me.”<sup>38</sup>
21. People with intellectual and developmental disabilities and their families are among the least considered groups in society. They are often neglected, disadvantaged and

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<sup>35</sup> Pontifical Council for Justice and Peace. *The compendium of the social doctrine of the Church*. Vatican City: Libreria editrice Vaticana, 2005, no. 186. Available online at: [http://www.vatican.va/roman\\_curia/pontifical\\_councils/justpeace/documents/rc\\_pc\\_justpeace\\_doc\\_20060526\\_compendio-dott-soc\\_en.html](http://www.vatican.va/roman_curia/pontifical_councils/justpeace/documents/rc_pc_justpeace_doc_20060526_compendio-dott-soc_en.html)

<sup>36</sup> John Paul II, *Apostolic Exhortation Familiaris Consortio* (November 22, 1981), no. 45.

<sup>37</sup> Pontifical Council for Justice and Peace. *The compendium of the social doctrine of the Church*, no. 182. The term *preferential option for the poor* was first coined by Gustavo Gutiérrez in 1967, although the notion underlying it has biblical and patristic roots. The term was adopted in the documents of the Latin American Bishops' Conference meeting in Medellín and Puebla, and also subsequently in papal documents, e.g. John Paul II, *Tertio millennio adveniente* (1994), n. 51: “...if we recall that Jesus came to ‘preach the good news to the poor’ (Matthew 11:5; Luke 7:22), how can we fail to lay greater emphasis on the Church’s preferential option for the poor and the outcast?”

<sup>38</sup> Matthew 25:40.

vulnerable. Members of society should have special concern for them and for their needs.

*H. Show solidarity with people with intellectual and developmental disabilities and their families in their suffering*

22. Human life is inherently limited. Pain, illness, disability, suffering and dying are part of any human life. Reason alone can offer no complete explanation or solution for the mystery of pain and suffering in human lives or for death. Nevertheless, many human beings can experience personal growth in adversity and are supported by the solidarity and love that is offered to them by their families and community.
23. For Christians, there can be hope in the midst of life's limitations. Christians are invited, as co-operators in building God's kingdom, to mitigate the adverse effects of illnesses and disabilities, including pain and suffering, as much as possible. Still they are aware that all pain and suffering in human beings, and the reality that all human beings are mortal, can never be completely eliminated in history. Christians believe that, in uniting themselves to Christ in his suffering on the cross, those who suffer and mourn can find meaning and a capacity to serve by participating in Christ's ongoing redemptive work.<sup>39</sup> Furthermore suffering always calls for solidarity by Christians with those who suffer and mourn. This is exemplified by the figure of the Good Samaritan in the Gospel according to Luke. Christian solidarity is manifested through a "sincere gift of oneself" by showing heartfelt concern, being with those who suffer and mourn, and providing loving care and support.<sup>40</sup>
24. Like all human beings, people with intellectual and developmental disabilities experience pain, suffering and mourning. They might have challenges in coping with these experiences and communicating their distress to health care providers. They and their families might be living in isolation without much attention or support from the rest of the community. For health care providers, showing solidarity means, most importantly: (a) establishing trust and empathy within the therapeutic relationship, (b) acknowledging the pain, suffering and mourning that people with intellectual and developmental disabilities and their families experience, and (c) providing support in times of distress. Health care providers should be trained to recognize the signs and symptoms of distress in people with intellectual and developmental disabilities and their families. They should also be trained to address pain and suffering appropriately by clarifying their likely sources and by offering or recommending environmental changes, social supports and holistic interventions for the human dimensions of suffering, in addition to biomedical interventions.

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<sup>39</sup> John Paul II, Apostolic Letter *Salvifici doloris* (Feb. 11, 1984), no. 27: "Faith in sharing in the suffering of Christ brings with it the interior certainty that the suffering person "completes what is lacking in Christ's afflictions; the certainty that in the spiritual dimension of the work of Redemption *he is serving*, like Christ, *the salvation of his brothers and sisters*. Therefore he is carrying out an irreplaceable service." Available online at: [http://www.vatican.va/holy\\_father/john\\_paul\\_ii/apost\\_letters/1984/documents/hf\\_jp-ii\\_apl\\_11021984\\_salvifici-doloris\\_en.html](http://www.vatican.va/holy_father/john_paul_ii/apost_letters/1984/documents/hf_jp-ii_apl_11021984_salvifici-doloris_en.html)

<sup>40</sup> *Ibid.*, no. 28.

## Recommendations

Based on the ethical framework expressed above, the following are some recommendations proposed for health care practices and policy development regarding the health care of people with intellectual and developmental disabilities and their families. The aim here is not to provide a comprehensive list of recommendations but to focus on those medical, ethical and policy issues that participants in the 6<sup>th</sup> International IACB Colloquium thought are the most significant.

### *Positive regard*

25. Within health care, and in society generally, we should be committed to *being with* people with intellectual and developmental disabilities and their families, promoting positive regard for them, being open to learning from them, and building mutually supportive relationships.
  - a. Everyone should promote the use of terminology and language that reflects respect for people with developmental disabilities as valued human beings with an identity that is not reducible to just their disabilities.
  - b. Those making decisions regarding health care, policies, and the allocation of resources affecting people with intellectual and developmental disabilities and their families should always take into account their views and perspectives. If processes and structures do not currently exist to do so, they should be created.
  - c. In addressing the needs and concerns of people with intellectual and developmental disabilities and their families, health care providers should work in partnership with them. They should enable and support whatever such people can offer and contribute to improving their health and lives as much as possible.
  - d. Those responsible for training health care providers should establish opportunities for learners to encounter and relate to people with intellectual and developmental disabilities and their families. Such experiences are needed to enhance understanding of the lives of people with intellectual and developmental disabilities and their families, and to develop the dispositions and skills necessary to communicate and relate well with them.
  - e. Health care providers and health care policy makers should be educated to use ethical reasoning that is applicable to interventions for *any* person. They should not base decisions on uninformed attitudes, such as the conflation of disability with inevitable or intolerable suffering, and on presumptions about the low quality and worth of another person's life with intellectual and developmental disabilities.<sup>41</sup>

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<sup>41</sup> On the philosophical and ethical difficulties of evaluating the sufferings of persons with intellectual and developmental disabilities, see Licia Carlson, *The faces of intellectual disability: Philosophical reflections*. Bloomington, IN: Indiana University Press, 2010, 177-187.

Decision making and consent

26. Many people with intellectual and developmental disabilities are capable of apprehending what is good and of making free, informed and value-based decisions. Like everyone else, their capacity to do so varies according to their level of intellectual functioning, the type and complexity of decision involved, and personal and circumstantial factors such as a lack of relevant experience, extreme fear due to adverse past experiences, learned acquiescence, or the presence of a mental illness that affects decision making.
- a. Health care providers should support the participation of people with intellectual and developmental disabilities as much as possible in making decisions regarding their health care, according to the capacity of such individuals to do so.
  - b. Health care providers should always conduct a thorough and appropriate assessment of the capacity of adults with intellectual and developmental disabilities to make decisions regarding their care and to give consent. They should be trained to use assessments and means of communication that are adapted to the individual's level of functioning and communication. Such assessments are important not only for people with moderate intellectual and developmental disabilities, in whom the capacity to provide free and informed consent is uncertain, but also for those with mild and borderline intellectual and developmental disabilities, in whom this capacity might routinely, but sometimes mistakenly, be assumed.
  - c. In assessing capacity, health care providers should ask for the input and assistance of family members and others who know the person well. These caregivers might be able to supply information relevant to an assessment and help with communication and interpretation.
  - d. If an individual with intellectual and developmental disabilities has been assessed to be incapable of making a free and informed decision, and his or her substitute decision maker<sup>42</sup> does not know this individual well, the substitute decision maker should consult those who do know the individual. This is particularly important when people with intellectual and developmental disabilities do not have family members who are involved and for whom a public guardian or trustee has been appointed.
  - e. Substitute decision makers of people with intellectual and developmental disabilities should take into account the good of the whole person on whose behalf they are making the decision.<sup>43</sup> They should be supported to apply ethical reasoning to distinguish between ethically obligatory and ethically optional health care interventions

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<sup>42</sup> Other possible legal terms for *substitute decision maker* include proxy, proxy decision maker, representative, surrogate, or advocate.

<sup>43</sup> See Edmund Pellegrino's explanation of the four aspects of the overall good of a patient: Pellegrino ED. The internal morality of clinical medicine: A paradigm for the ethics of the helping and healing professions. *Journal of Medicine and Philosophy* 2001; 26(6): 559-579, at 569-573.

for the person on whose behalf they are making a decision.<sup>44</sup> Health care providers, social workers, ethicists and chaplains who are trained in ethics, and especially those who are knowledgeable about people with intellectual and developmental disabilities, can provide this support.

*Health care, illness prevention and health promotion*

27. As a society, we should be committed to making adaptations and providing support so that people with intellectual and developmental disabilities are able to access available health care resources and services that are offered to all. We should also ensure that the particular health issues of people with intellectual and developmental disabilities are addressed through appropriate care and support.
  - a. Educators should teach health care providers about the importance of continuity of care, as well as effective interdisciplinary care, to meet the multiple and complex health issues that people with intellectual and developmental disabilities and their families face. They should also help health care providers to develop the attitudes and skills needed to complete assessment and management plans that reflect holistic care.
  - b. Those who are responsible for allocating resources and planning the delivery of services in health systems should support interdisciplinary, holistic and well coordinated care for people with intellectual and developmental disabilities. They should take steps to ensure that care that might require more attention and time for health care providers to undertake effectively or a greater extent of interdisciplinary collaboration and coordination than for the general population is available to people with intellectual and developmental disabilities and their families.
  - c. Health care providers should be educated regarding the particular health issues of people with intellectual and developmental disabilities, e.g., through practice guidelines and other resources, including the importance of attending to preventive care and health promotion.<sup>45</sup>
  - d. Health care providers should be educated and supported in ways to communicate and collaborate effectively and ethically. Such collaborations usually involve sharing health and other relevant information. This should be done in the best possible way both to respect the privacy of people with intellectual and developmental disabilities and their families as well as to make available information that is essential for effective and coordinated care.

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<sup>44</sup> For a helpful elaboration on the distinction between ethically obligatory (“ordinary” or “proportionate”) interventions and ethically optional (“extraordinary” or “disproportionate”) interventions in the Catholic moral tradition, which has been applied by ethicists outside this tradition and in the law, see Sullivan SM. The development and nature of the ordinary/extraordinary means distinction in the Roman Catholic tradition. *Bioethics* 2007; 21(7): 386-397.

<sup>45</sup> There is strong evidence supporting the value of annual comprehensive health assessments by primary health care providers. See, for instance: Lennox N, Bain C, Rey-Conde T, Purdie D, Bush R, Pandeya N. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: A cluster randomized trial. *International Journal of Epidemiology* 2007 Feb; 36(1): 139-46.



- e. In allocating resources and offering treatment options, health care providers should reject criteria that put people with intellectual and developmental disabilities at a disadvantage relative to others.<sup>46</sup>
- f. Administrators of health care facilities and health care providers should ensure that their facilities are accessible to people with mobility, sensory and sensory sensitivity challenges, or can be readily adapted to meet the needs of such people.
- g. Public health officials and health care providers should ensure that materials and other media to communicate information about health care, illness prevention and health promotion are adapted to the communication level and particular needs of people with intellectual and developmental disabilities.
- h. In developing management plans and coordinating care, health care providers should be especially attentive to the vulnerabilities and needs of people with intellectual and developmental disabilities and their families at the time of diagnosis and during periods of loss, such as the death of a loved one, or major life changes such as the transition to adult life or aging.

*Spiritual and pastoral care*

- 28. Spiritual and pastoral care should be a component of the interdisciplinary, holistic health care offered to people with intellectual and developmental disabilities and their families.
  - a. All health care providers should be attentive to the spiritual issues of people with intellectual and developmental disabilities and their families and support them with the offer of spiritual and pastoral care from those trained to provide such care and members of the clergy belonging to the person's or family's faith tradition. Health care providers and teams that develop a management plan should be informed about spiritual and religious perspectives regarding care that are relevant for the person and his or her family.
  - b. Those who plan health care services should recognize the importance of the role of trained providers of spiritual and pastoral care, and provide resources to ensure that such care is available to people with intellectual and developmental disabilities and their families.
  - c. All providers of spiritual and pastoral care should be educated about the spiritual issues and theological questions that are raised by people with intellectual and developmental disabilities and their families (e.g., Why me? Is God punishing me?) and different ways to help nurture and support their spiritual and faith journeys throughout their lives.
  - d. Faith communities should commit to making people with intellectual and developmental disabilities and their families welcome, affirm their belonging to these communities, and enable them to participate in worship, other rites and social activities.

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<sup>46</sup> Anthony Fisher, The ethics of health care allocation. *Catholic Medical Quarterly* 1993; 44(4): 13-20.

*Prenatal counselling, screening and diagnosis*

29. Genetic and other medical tests can be used to screen for and diagnose some conditions associated with intellectual and developmental disabilities during pregnancy, such as Down syndrome and Fragile X syndrome, for which there are presently no available prenatal therapies. The rate of parental decisions to abort their developing child following prenatal diagnosis of a condition associated with intellectual and developmental disabilities is very high.<sup>47</sup> There was unanimity among participants in this colloquium that prenatal screening and diagnosis should be guided by the view that all human beings have equal worth and not the view that people with a disability are “imperfect” human beings.<sup>48</sup> Furthermore:
- a. Everyone in society should support pregnancy as a time of unconditional attachment between parents and their developing unborn child.
  - b. Health care providers should be aware of the negative judgments regarding people with disabilities that underlie the increasingly prevalent mentality in society that a couple’s pregnancy is conditional until their developing unborn child is certified by genetic and other tests to be free of “defects”.
  - c. No person in society should blame parents for conceiving a child with a condition associated with intellectual and developmental disabilities. Everyone in society should promote sufficient resources and supports for parents with such a child.
  - d. Parents, in considering genetic screening or testing, should have counseling concerning the ethical issues involved.
  - e. The decision of parents and certain health care providers not to participate in prenatal screening or diagnosis for ethical reasons should be supported by all and should be protected by law and policy.
  - f. Genetic screening and testing, including maternal serum screening or the emerging technology of cell free fetal DNA (cffDNA) screening, should not be offered as routine prenatal care.<sup>49</sup>

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<sup>47</sup> For example, the rate of abortion is between 60-90% in the United States when Down syndrome is prenatally diagnosed. See Natoli, JL et al. Prenatal diagnosis of Down syndrome: A systematic review of termination rates (1995-2011). *Prenatal Diagnosis* 2012; 32: 142-153.

<sup>48</sup> Some ethicists have argued that prenatal genetic testing always entails a negative evaluation of the life of people with a disability. See, for example, Erik Parens and Adrienne Asch. Special supplement: The disability rights critique of prenatal genetic testing: Reflections and recommendations. *Hastings Center Report* 1999 (Sept.-Oct.); 29: S1-S22. Parens and Asch express the disability rights critique of genetic testing as follows: “First selective abortion expresses negative or discriminatory attitudes not merely about a disabling trait, but about those who carry it. Second, it signals an intolerance of diversity not merely in the society but in the family, and ultimately it could harm parental attitudes toward children.” Some participants in this colloquium also voiced similar concerns. See Christoph von Ritter, “Eugenics in Modern Societies”. There was, however, not a consensus among participants on this issue.

<sup>49</sup> CffDNA are fragments of fetal genetic material found in the mother’s plasma. CffDNA screening can detect risks of chromosomal disorders such as Down syndrome at an early stage during pregnancy (typically around 10 weeks).

- g. In counseling parents or prospective parents, health care providers should be informed by perspectives of people with intellectual and developmental disabilities and their families. Counselors should refer prospective parents to support and advocacy groups for parents with children with intellectual and developmental disabilities.<sup>50</sup>

*Prevention of the causes of intellectual and developmental disabilities*

- 30. Health care providers and developers of health care policy should support and promote research and interventions to prevent prenatal or postnatal exposure to environmental and other toxins (e.g., ionizing radiation, toxic chemicals, lead and mercury), infections, and perinatal factors that have been linked to intellectual and developmental disabilities.

*Safety and avoiding harm in health care*

- 31. In relating to people with intellectual and developmental disabilities, health care providers should be committed to promoting their safety and minimizing avoidable risks of harm.
  - a. As part of preventive care, health care providers should address unhealthy and unsafe environments in which people with intellectual and developmental disabilities live as well as barriers in the health care and social support systems that risk causing harm.
  - b. Health care providers should adapt their practices to minimize the barriers and distress of people with intellectual and developmental disabilities and their caregivers.
  - c. Behavior might be the only way through which a person with intellectual and developmental disabilities can communicate experiencing pain, loneliness or some other distress. In addressing behaviors of a person with intellectual and developmental disabilities that raise concerns about the safety of the person or others (e.g., family member, support worker, co-resident, members of the public), health care providers should always proceed with the least intrusive and least restrictive options available to promote safety from that person's perspective. This should always be followed up with a review of the possible underlying causes of the behavior.
  - d. People with intellectual and developmental disabilities are often inappropriately prescribed medications. Health care providers should avoid harm by regularly reviewing the appropriateness of the medications that their patients are taking and monitoring their effects and interactions.

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<sup>50</sup> In Brian Skotko's studies, 99% of persons with Down syndrome reported being happy with their lives, 95% of children had good relationships with their siblings with Down syndrome, and 97-99% of parents expressed love and pride for their children with Down syndrome. See Skotko, BG., et al. Having a brother or sister with Down syndrome: Perspectives from siblings. *American Journal of Medical Genetics Part A* 2011;155: 2348–2359; Skotko, BG et al. Having a son or daughter with Down syndrome: Perspectives from mothers and fathers. *American Journal of Medical Genetics Part A* 2011;155: 2335–2347. Skotko, BG, et al. Self-perceptions from people with Down syndrome. *American Journal of Medical Genetics Part A* 2011;155: 2360–2369.

- e. Abuse and neglect of people with intellectual and developmental disabilities occurs too frequently, often perpetrated by individuals or groups known to them.<sup>51</sup> In the education of health care providers, particular attention should be paid to recognizing and addressing signs of abuse and neglect in people with intellectual and developmental disabilities, especially those who might not be able to communicate that they are being abused or neglected. Health care providers should also be educated to recognize and address risk factors among families and other care providers for perpetrating abuse and neglect.

*Behavioral and mental health issues*

- 32. Behavioral and mental health issues are frequent in people with intellectual and developmental disabilities. They are able to communicate in various ways, however, and this communication is crucial to understanding the origins of their behavior and mental health issues.<sup>52</sup> Attentive observation of people with intellectual and developmental disabilities in the application of holistic approaches should inform the ethical management of such issues.
  - a. Health care providers should be as ready to assess and address behavioral and mental health issues in people with intellectual and developmental disabilities as they would when they encounter these issues in people without intellectual and developmental disabilities.
  - b. Health care providers should be educated to understand that some behavioral issues in people with intellectual and developmental disabilities, such as aggression and self-injury, might not be a symptom of a mental illness. It could be an indication of distress due to a health-related condition or due to environmental factors, such as inadequate supports or loss of supports. Hence health care providers should be trained to develop effective communication with people with intellectual and developmental disabilities and to apply a comprehensive and holistic assessment of their behaviors.<sup>53</sup>
  - c. Health care providers should seek input and assistance from people with intellectual and developmental disabilities and their family and other care providers to establish a shared understanding of the basis of problem behaviors and to discuss and implement possible management plans.

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<sup>51</sup> Discussion during the colloquium highlighted the ethical issue of health care providers prescribing contraceptives to women with intellectual and developmental disabilities who are known or suspected of being sexually abused without addressing the abuse itself. This ethical issue is one that merits attention.

<sup>52</sup> Individuals with some language skills might communicate their distress through personal narratives and autobiographies; those with limited or no use of words may express themselves through non-verbal gestures and through their day-to-day behaviors. Their communication mode is unique and hard to interpret for people who do not know them well. Better understanding of their distress can occur in the context of an individual's relationships with health care providers, which often take time to develop.

<sup>53</sup> See, for example: Bradley EA, Hollins S. Assessment of patients with intellectual disabilities. In Goldbloom DS, ed. *Psychiatric clinical skills*. Revised 1<sup>st</sup> edition. Toronto, ON: Centre for Addiction and Mental Health, 2010, 257-276.

- d. Health care providers should offer positive approaches and holistic therapies to manage problem behaviors as a first option whenever there is a reasonable hope of benefit. Although intrusive and restrictive measures might sometimes be ethically justified for short-term relief of a person with an intellectual and developmental disability or to prevent harm to those in the person's community of support, the least intrusive and least restrictive means for that person should be tried first.
- e. Because there is evidence of long-term harm and no evidence of long-term benefit when antipsychotic medications are inappropriately prescribed for problem behaviors, such medications should not be prescribed as a first-line intervention by physicians and nurse practitioners for problem behaviors.
- f. Assessment and management of mental illness in people with intellectual and developmental disabilities require the support of mental health professionals who have knowledge and experience in this area. Those who plan health services should ensure that such resources and supports are available.
- g. When psychotropic medications are prescribed for a person with intellectual and developmental disabilities and a mental illness, these medications should be monitored. The basis for prescribing these medications and effects on the overall well being of the person should be reviewed at regular intervals.
- h. As part of their duty to care for people with intellectual and developmental disabilities, health care providers should offer preventive care and health promotion in relation to behavioral and mental health issues. This involves, for example, screening for and addressing insufficient supports, loss, abuse or neglect, risk of addiction to alcohol, drugs or gambling through the influence of others, developing an integrated emergency response plan for behavioral crises involving the person's support system, and establishing a baseline of functioning to aid early diagnosis of dementia in persons with predisposing conditions such as Down syndrome.
- i. Those who develop health care policies and plan health services should ensure that there is continuity and coordination of care, especially for those who address primarily physical health issues and those who focus on behavior and mental health issues.

*Intimacy in friendships and romantic relationships*

- 33. People with intellectual and developmental disabilities desire intimacy and a loving, supportive community. They flourish by sharing their lives with others.<sup>54</sup> Like all human beings, their sexuality is a part of who they are.
- a. All in society should promote inclusion and other conditions that make it conducive for people with intellectual and developmental disabilities to form friendships, e.g., by being open to encountering and getting to know them, sponsoring social activities to which they are invited and welcomed, and offering coaching and counseling to develop their

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<sup>54</sup> As an illustration of this, an adult with intellectual and developmental disabilities and a self-advocate at the colloquium, Kareem Elbard, was asked what was at the top of his list of wishes for his life. He replied, "Someone to share my life with."

relationship skills. Organizations should remove restrictions that impede socializing of individuals with intellectual and developmental disabilities.

- b. Young persons with intellectual and developmental disabilities can benefit from education and counseling regarding sexuality, romantic relationships, marriage and parenthood that are adapted to their level of functioning and emotional maturity. In partnership with parents, who can contribute cultural or faith-based perspectives, health care providers should offer young persons with intellectual and developmental disabilities access to such education and counseling services.
- c. As part of primary care, health care providers should discuss health concerns that persons with intellectual and developmental disabilities and their families have regarding sexuality. They should screen for potentially harmful sexual practices or exploitation and address these through education, counseling, and ensuring that the person receives protection.
- d. Health care providers should offer access to family counseling if disagreements arise within families of adults with intellectual and developmental disabilities who are assessed to be capable of making informed decisions regarding their relationships and sexuality. Such counseling should be attuned to the cultural and faith traditions of the patient and the patient's family.
- e. Limits on the privacy and freedom of adults with intellectual and developmental disabilities that are established by their family members and other caregivers, e.g., through supervision or restrictions, must be justified by significant reasons relating to the well being of those adults and their communities. Such reasons include situations where limits are set because sexual practices are harmful and exploitive, including undermining supportive relationships on which the person depends.
- f. There should be no universal prohibition against people with intellectual and developmental disabilities marrying or being parents.<sup>55</sup>
- g. Governments, in partnership with social service organizations, should provide resources for parents with intellectual and developmental disabilities who require education in parenting skills adapted to their needs, counseling, and additional supports for them and their children.
- h. No guardian or substitute decision maker of a person with intellectual and developmental disabilities should have the authority to consent on behalf of that person to sterilization with the intention of preventing fertility. No health care provider should participate in sterilization for this purpose.<sup>56</sup>

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<sup>55</sup> Participants identified the need to reflect on and discuss how such decisions should be made in individual cases but did not develop specific guidelines during this colloquium.

<sup>56</sup> Some participants disagreed with this point, arguing that decisions regarding sterilization of people with intellectual and developmental disabilities who do not have the capacity to consent should be analyzed ethically on a case-by-case basis, taking into consideration the benefits and the harms to the overall well being of the person involved. This issue merits further research and discussion.

- i. Providers of health care to parents with intellectual and developmental disabilities and to their children should be attentive to changing family dynamics through time and the vulnerabilities and needs of children in such families. They should encourage parents with intellectual and developmental disabilities and their support system to develop advance care plans for the birth of a child and for possible periods of crisis and life transitions. Health care providers should support maintaining and strengthening family bonds and relationships through offering education and counseling.

*Aging*

34. An issue of specific concern to families is the health care and support of people with intellectual and developmental disabilities in old age, particularly when they will no longer have living or involved family members.<sup>57</sup>
  - a. All members of society should show solidarity with elderly people with intellectual and developmental disabilities, particularly those without the support of family members. Those who are responsible for the allocation of resources and for planning services for people with intellectual and developmental disabilities in the government, and volunteers in the community, should take steps to ensure that such people continue to have sufficient resources and a support system that will enable them to participate as much as possible in making decisions regarding their care and to receive appropriate health care and supports as they age.
  - b. Those who are responsible for the allocation of health care resources and health care providers should use the same medical and ethical criteria for offering health care interventions to address potentially life-shortening conditions to persons with intellectual and developmental disabilities (e.g., pace makers) as they would to people without such disabilities.

*Advance care planning, end-of-life care and euthanasia*

35. People with intellectual and developmental disabilities who are seriously ill or dying should receive the best available end-of-life care that is adapted to their level of functioning and needs.
  - a. Advance care planning can often make a positive difference to emergency care for potentially life-threatening events and end-of-life care of people with intellectual and developmental disabilities. Health care providers should engage in advance care planning and enable people with intellectual and developmental disabilities to participate in such planning, to the extent of their abilities. They should take into account the input and support of the person's family and others who know the person well.
  - b. People with intellectual and developmental disabilities who have a progressive, serious and incurable illness or are dying should be provided appropriate palliative care. The decision to change the plan of care of a person with intellectual and developmental

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<sup>57</sup> The health effects of aging might be accelerated in persons with some conditions associated with intellectual and developmental disabilities, e.g. Down syndrome.

disability from curative to palliative mode should be based on the same criteria that would be used for a person who does not have such a disability. The disability itself should not be the decisive factor in a decision to abandon curative or life-sustaining interventions.<sup>58</sup>

- c. Decisions to withhold or withdraw life-prolonging interventions from an infant, child or adult with an intellectual and developmental disability should always be based on determining that the intervention offers no reasonable hope of benefit or is excessively burdensome.<sup>59</sup> In determining benefits and burden, having an intellectual and developmental disability alone never suffices to justify forgoing an intervention. The death of the person with intellectual and developmental disabilities should not be the intent.<sup>60</sup>
- d. Euthanasia of people with intellectual and developmental disabilities contravenes respect for human life and the health care provider's duty to care. It should not be practiced or legalized.

#### Research

- 36. Governments, health care systems and health care providers should support regular monitoring and assessment of the quality of health care of people with intellectual and developmental disabilities. They should give priority in planning or funding research to those questions or areas of inquiry that are likely to improve health care and health outcomes for people with intellectual and developmental disabilities. They should also support research to enhance partnerships among people with intellectual and developmental disabilities, their families, and their health care providers.
- 37. Research should include reflections and discussions on ethical issues. Research on ethics should be interdisciplinary and open to the perspectives of faith communities.
- 38. Research should be informed by the perspectives of people with intellectual and developmental disabilities and their families.

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<sup>58</sup> There are many published reports of confusion concerning the distinction between disability and terminal illness arising out of the notion that a disability is worse than death. For a personal account of discrimination against people with disabilities who choose to live, see William J. Peace. Comfort care as denial of personhood. *Hastings Center Report* 2012 (42): 14-17.

<sup>59</sup> John Paul II, *Evangelium vitae* (1995), no. 65: Euthanasia is "an act or omission which of itself and by intention causes death, with the purpose of eliminating suffering." When the intention to withhold or withdraw life-prolonging intervention is based on the judgment that such an intervention has no reasonable hope of benefit and is excessively burdensome, and not on an intention to bring about death, this omission or act is not committing euthanasia. The *Declaration on euthanasia* of the Sacred Congregation on the Doctrine of the Faith (1980) explains why: "When inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted."

<sup>60</sup> For a clear explanation of this point, see Sulmasy D. Killing and allowing to die: Another look. *The Journal of Law, Medicine and Ethics* 1998; 26(1): 55-64.



39. Ethics review of health care research involving people with intellectual and developmental disabilities should recognize the capacity of some individuals with intellectual and developmental disabilities to give informed consent to research, according to the same guidelines proposed above for consent to health care interventions.

### **Conclusion**

40. This statement proposes an ethical framework that emphasizes the intrinsic value of people with intellectual and developmental disabilities and their belonging to the human family. It orients health care providers toward the good of being with such persons, that is, encountering, accompanying and relating to them *as persons* and not merely engaging in doing things to and for them. It emphasizes the self-giving love of health care providers as the basis of ethical health care. According to this ethical framework, the meaningful participation of people with intellectual and developmental disabilities and their families in health care and in our communities should always be promoted. Some implications of this ethical framework as they pertain to health care and health policy have been elaborated in the recommendations of this statement.
41. The key recommendations highlighted in this statement are that:
- Health is a basic condition for the participation of people with intellectual and developmental disabilities in our communities. They should have adequate access to health care and also health care that is adapted to their particular needs.
  - Community resources should be made available to enable health care providers to care well for people with intellectual and developmental disabilities. These include adaptations to practices to promote safety, enhance communication, continuity of care, relationships that enable the health care provider to get to know the person and his or her world, partnerships in care with the person and his or her family members and other primary caregivers, guidelines, training and support for health care providers, holistic and interdisciplinary interventions, and resources for research.
  - Prenatal genetic testing and health care of people with intellectual and developmental disabilities should be guided by positive attitudes regarding their intrinsic value and worth, and their belonging to the human family, at every stage in their lives.
  - Health care providers should develop relationships with people with intellectual and developmental disabilities and their families that are characterized by trust and openness to mutual learning. When assessing decision-making capacity and the physical, behavioral and mental health issues of people with intellectual and developmental disabilities, health care providers should make an effort to learn the personal ways by which each person communicates and to get to know the person, his or her family members and other primary caregivers, and their circumstances in order to offer interventions, support and advocacy that are appropriate for them.
  - The families and other primary caregivers of people with intellectual and developmental disabilities can offer health care providers and developers of health policy important help. Health care providers should strive to attain a shared

understanding of health issues and how to address them in partnership with people with intellectual and developmental disabilities and their families and other caregivers. Developers of health policy should promote processes and structures that enable regular discussions with people with intellectual and developmental disabilities and their families on relevant matters.

- Family members and other caregivers have needs that should be assessed and addressed by health care providers and given priority by developers of health policy and those responsible for the allocation of health care resources.
- People with intellectual and developmental disabilities should be supported to form and sustain close and meaningful friendships and other social relationships. These might include romantic relationships, marriage and parenthood in certain instances.
- People with intellectual and developmental disabilities should be encouraged and supported to participate in making decisions, plans and policies regarding their own health care to the extent of their abilities. The capacity of people with intellectual and developmental disabilities to make such decisions should be assessed in ways that are appropriate to the person's communication and level of functioning. Health care providers should enable support in decision making from family members and other caregivers who know the person well.
- Conflicts regarding the decisions of individuals with intellectual and developmental disabilities who are capable of making them and their health care providers, families or supportive communities should be resolved through discussion, education and counseling. Efforts should be made to accommodate the decisions of capable people with intellectual and developmental disabilities as much as possible while maintaining or enhancing the care and supports that they need.
- When people with intellectual and developmental disabilities engage in behaviors that are concerning, the underlying causes of these behaviors should be sought and addressed.
- When interventions are necessary to ensure the safety of an individual with intellectual and developmental disabilities and/or other people, the least intrusive and least restrictive interventions from the perspective of the individual should always be tried first.
- Health care of people with intellectual and developmental disabilities and their families should include attention to their spiritual issues. They should be welcomed within faith communities. Spiritual and pastoral care adapted to their needs should be offered.

The last and most important word in this statement belongs to a young man with intellectual and developmental disabilities who participated in the 6<sup>th</sup> International IACB Colloquium: "Please help me to make sure that people with developmental disability...have

their inner beauty appreciated and not be judged by their appearance or labels given to them.”<sup>61</sup>

### Signatories

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<sup>61</sup> Elbard K. My advocacy wish list. Presentation at the 6<sup>th</sup> International IACB Colloquium, Rome, June 10, 2013.

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