
Bioethics Outlook

Plunkett Centre for Ethics

Australian Catholic University,
St Vincent's Health Network & Calvary Healthcare

Volume 31, No 4

December, 2020

Promoting capabilities to make healthcare decisions

Consensus Statement of the 9th IACB International Colloquium

1 Ethical framework

Five foundational ethical principles should guide caregivers and healthcare providers in promoting capabilities of persons to make healthcare decisions. Each principle is based on (a) philosophical reasoning and (b) shared foundations among Christians. Members of other faith communities also share many of these principles. Some also have been articulated in documents upholding universal human rights, such as the United Nations' *Convention on the Rights of Persons with Disabilities*.ⁱ

1. Respecting inherent human dignity

All human beings have inherent dignity.ⁱⁱ Our dignity is not diminished or lost when we experience impaired cognitive functioning, disability, compromised mental health or addiction.

- For Christians, every human being is a unique being created in the image and likeness of God, unconditionally loved by God, and called to enjoy divine friendship beginning in this life.ⁱⁱⁱ Hence each is of inestimable worth and should be honoured and respected as such by others in the human family.

2. **Supporting one another**

Human beings are relational and inter-dependent beings.^{iv} We support one another in varying degrees to foster health and well-being, develop and realize capabilities, form and live out authentic values, and be resilient when experiencing adversity and suffering. Relationships in which persons experience mutual support (e.g., knowing others and being known, caring reciprocally for and about others) promote solidarity and a sense of belonging among members of a community.^v They enable each person to participate in and contribute to the common good.^{vi}

- All human beings are called to support and love one another as children of God. Mutuality in human relationships reflects the loving relationship among divine Persons of the Trinity.^{vii}

3. **Being responsible stewards**

Life is the most basic of human goods because it is the condition for realizing other goods. The right to life and the right to the highest attainable standard of health in a community are fundamental human rights.^{viii} Human beings have responsibility for conserving and promoting their health with support from others as needed.

- Life and health are gifts from God for which all are called to exercise good stewardship.^{ix}

4. **Living authentically**

The authentic values of human beings are integral to the persons they are. Regardless of their level of functioning, all human beings intend and enjoy what contributes to their well-being as whole persons (e.g., health, security, having positive connections with other persons, having a sense of belonging, engaging in meaningful work or leisure, encountering beauty, and fulfilling spiritual longings.)^x They usually develop, affirm and live out these authentic values through interacting with others in the communities to which they belong (e.g., family, friends, members of their cultural or religious communities).

- God is the source of all that is good and, as the supreme good, is what human beings are seeking when they intend values that are authentic.^{xi}

5. **Being just**

An important aspect of justice is equity. This involves attending to the specific needs of persons so that all might have equal opportunity to attain the shared benefits of a community or the common good. Another aspect of justice is restoration, which redresses inequities that affect the most vulnerable members of a community.^{xii} Vulnerability in making healthcare and other decisions can be associated with many factors. Some of these are related to impaired cognitive functioning, which can include environmental and social factors such as the impact of stress or trauma, barriers to communicating, being socially isolated or lacking appropriate and adequate supports. Being just entails assiduously finding

ways to accommodate, support, and care for persons who experience vulnerabilities in making healthcare and other decisions.

- Christians are called to have special commitment to the poor: “The primary purpose of this special commitment to the poor is to enable them to become active participants in the life of society. It is to enable all persons to share in and contribute to the common good. The ‘option for the poor,’ therefore, is not an adversarial slogan that pits one group or class against another. Rather it states that the deprivation and powerlessness of the poor wounds the whole community.”^{xiii} The poor in health care are not only people who are economically disadvantaged but also those who are on the margins of healthcare systems because they are not full participants in it.

2 Considerations

All patients should be participants in their health care.

- a. The presence of an intellectual and developmental disability, progressive neuro-cognitive impairment, compromised mental health or addiction does not, by itself, entail that a patient lacks capacity to make healthcare decisions or contribute to them.
- b. The relationship of patients, caregivers on whom they depend, and their healthcare providers is collaborative. Decision making among them should be shared, with patients being offered accommodations and supports as needed to participate in making decisions regarding goals for their own health care and treatments.
- c. There can be a range of such decision-making accommodations and supports. These include adapting environments and offering interventions to mitigate stress or trauma surrounding decision making, reducing barriers to communicating, ensuring sufficient time for making decisions, training or mentoring, and enlisting help from close caregivers and other decision-making supporters who know the patient well.
- d. Decision-making capabilities of patients can vary with the type of healthcare decision to be made. Some patients might have need for a greater degree of support in making some decisions than others. For example, they might need more support for decisions that are complex, those that involve unfamiliar treatments, and when there is great uncertainty regarding a treatment’s benefits, risks or burdens for the patient.
- e. There is a continuum of decision-making capabilities in patients. The law in various jurisdictions and the clinical judgment of healthcare providers usually determine a patient’s competence or capacity to make healthcare decisions somewhere along that continuum.^{xiv} However, we urge law makers and clinicians to recognize that autonomy is **relational** and that decision-making capacity can be **inter-dependent**.^{xv} When offered the help of one or

more decision-making supporters, many patients are capable of making healthcare decisions, and many more are capable of contributing to them to some degree.

f. Decisions in health care should always involve discerning the authentic values of patients in determining the good of their whole person. This discernment can be challenging with persons with profoundly impaired cognitive functioning, distorted thinking, absent or minimal ability to communicate in ways that other people can understand. Nonetheless, it is important to try to discern these patients' authentic values as best one can. Decision-making supporters, e.g., close caregivers and others who know such a patient well, can often reliably interpret this patient's authentic values. They can enable the patient to make healthcare decisions that both align with the authentic values of the patient and promote her or his health and overall well-being.

g. Some situations should be avoided or rectified if they occur in health care: (1) not recognizing a patient's capacity to make certain healthcare decisions when she or he is capable of doing so with support, and (2) not recognizing vulnerabilities that impair a patient's capacity to make certain informed or voluntary healthcare decisions without needed support (e.g., distorted thinking; impulsiveness; compulsiveness; trauma; learned helplessness).

h. Caregivers who support patients and promote their decision-making capabilities should themselves be offered adequate resources and supports to equip and sustain them in their important role.

i. Regrettably, many patients who need decision-making supporters lack them. We enjoin communities, especially faith communities, to enable persons who are socially isolated to develop friendships and other close, stable, and trusting relationships.

3 Recommendations

The following are practical ways of promoting capabilities of patients who might require different degrees of support to make healthcare decisions under different circumstances. The type and degree of decision-making supports offered should vary according to each patient's needs.

Recommendation	How various groups can do
1. <i>All patients should participate as much as possible in making</i>	<u>Patients:</u> Know that you may participate in making healthcare decisions that concern you. Ask to be involved and to be supported to do so.

<p><i>decisions regarding their own health care.</i></p>	<p><u>Caregivers:</u> Advocate for the person you care for to participate in making healthcare decisions when they are excluded. Know that your role in promoting decision-making capabilities of the person you care for is important. Ask about available resources and supports that you need for this role.</p> <hr/> <p><u>Healthcare providers (individuals and teams):</u> Always address your patient directly in clinical encounters.</p> <p>Get to know your patient as much as possible and any close persons your patient depends on for care and support in making healthcare decisions.</p> <p>Seek opportunities to be educated regarding accommodating patients to promote their decision-making capabilities and find out about tools and other resources to enable you to determine and offer different accommodations that patients might need.</p> <p><u>Healthcare organizations:</u> Establish or review policies with the goal of promoting patients' involvement as much as possible in making healthcare decisions (e.g., training staff, offering flexibility to accommodate patients, making available resources that patients and their decision-making supporters might need).</p>
<p><i>2. Recognize that patients have a range of needs for accommodation and support to be capable of making healthcare decisions. These accommodations and supports should be appropriate and adequate for their needs.</i></p> <p>a. Regarding all patients:</p>	<p><u>Healthcare providers:</u> Recognize that patients might need different types of accommodations and varying degrees of support depending on the decision to be made and depending on their circumstances.</p>

	<p>Adapt assessments to include assessing patients' needs for accommodations, including their need for one or more decision-making supporters.^{xvi}</p> <p>Assess also the need for input from an ethicist or spiritual care provider to help elicit and/or discern the patient's authentic values relevant to the decision.</p> <p><u>Researchers:</u> Contribute to advancing practices and policies that promote decision-making capabilities of patients by investigating factors conditioning patients' varying needs for accommodation and support and the efficacy of those accommodations and supports.^{xvii}</p>
<p>b. Regarding patients who are capable of making certain decisions with minimal assistance from decision-making supporters (i.e., <i>independently</i>)</p>	<p><u>Healthcare providers:</u> Remember that such patients might still need other accommodations besides decision-making supporters to promote their decision-making capabilities (e.g., adapting environments to reduce stress, addressing barriers to communicating, offering more time for making decisions).</p> <p>Encourage caregivers who might not recognize or accept independent decision-making capabilities of the person for whom they care to promote those capabilities.</p>
<p>c. Regarding patients who are capable of making certain decisions <i>inter-dependently</i>: Such patients need the help of one or more decision-making supporters to exercise their decision-making capabilities.</p>	<p><u>Healthcare providers:</u> Explore involving decision-making supporters first before recourse to substitute decision makers.^{xviii}</p> <p>If the patient cannot make the decision independently, ask whether there are one or more persons from whom the patient wants support to make the decision, and enlist the help of that person.</p> <p>Where the law permits, if the patient cannot indicate any decision-making supporter, engage with a close caregiver who can reliably interpret the patient's goals and authentic values to guide the decision.</p> <p>Offer guidance as needed to patients and caregivers to navigate the supported decision-making process.</p> <p>Develop plans for supported decision making that clarify the roles of all parties involved (e.g., plans for managing day-to-day health care decisions; advance care plans).^{xix}</p>

	<p>Where the law does not recognize the role of decision-making supporters, sometimes substitute decision makers might agree to involve such supporters with patients in making the decision, although the substitute decision maker would authorize it.^{xx}</p> <p><u>Researchers:</u> Develop and evaluate models, tools, and other resources to facilitate supported decision-making approaches to healthcare decision making.</p>
<p>d. Regarding patients who, even when their needs are accommodated and decision-making supporters assist them, are dependent entirely on others to make the healthcare decision.^{xxi} In such circumstances, decisions will still need to be made to promote and protect the patient's health and well-being as a person.</p>	<p><u>Healthcare providers:</u> Seek assent^{xxii} whenever possible even if the patient is deemed not capable of making healthcare decisions either independently or inter-dependently.</p> <p>For circumstances in which respecting a patient's non-assent entails risk of significant harm to the patient or to others, see (3) below.</p> <p>Facilitate communication of substitute decision makers who do not know the patient well with persons who are more familiar with the patient.</p> <p>While there are different standards in different jurisdictions for determining best interest regarding a specific treatment decision, such determinations should include considering the patient's goals and authentic values as discerned by their history and present circumstances, with the help of close persons who know the patient well.^{xxiii}</p>
<p><i>3. Protect safety of the patient and others from unintended harm resulting from the patient's refusing needed treatment.</i></p>	
<p>a. Various factors can compromise a patient's decision-making capabilities (e.g., episodes of florid psychosis, impulsivity). These can result in the patient refusing or not assenting to certain</p>	<p><u>Healthcare providers and caregivers:</u> In such situations, it is important for caregivers and healthcare providers to maintain the patient's trust as much as possible. Doing so increases possibilities of finding alternatives to prevent or reduce harm in ways acceptable to the patient.</p> <p>When healthcare providers assess a patient who refuses healthcare treatments that she or he needs, try to discern the reasons behind this refusal and address them. Also consider</p>

<p>healthcare assessments and interventions that she or he needs in order to avoid likely, significant, but unintended, harm to self or others.</p>	<p>factors that might compromise the patient’s decision-making capabilities.</p> <p>Work with patients when they are capable of making such treatment decisions, with supports as needed, to develop advance care plans. These plans might include enabling other persons (caregivers or healthcare providers) to authorize healthcare treatments that the patient will need when she or he is not capable of making such decisions.^{xxiv}</p> <p>When the patient lacks an advance care plan, and the risk of significant self-harm or harm to others is likely, work with substitute decision makers and persons who know the patient well to decide on immediate and effective medical or other interventions. Healthcare providers should first attempt options for harm-reduction or treatment that are least restrictive or aversive to the patient. Also, these interventions should align as much as possible with the best interpretation of the patient’s goals and authentic values.</p> <p>-Before isolating or confining patients, modify environments and routines and increase monitoring to prevent the patient from harming others if this is a concern.</p> <p>Recognize that family and other caregivers often depend on healthcare providers to guide patients to accept or assent to treatments that the patient needs. Appealing to the healthcare provider’s or team’s expertise and experience can help family and other caregivers to maintain the patient’s trust, alleviate caregiving burden, and harmonize conflicts within families.</p> <p>Review the reasons for, and the effects on the patient of, medical and other interventions provided during a crisis. Do this soon afterwards (within days) and regularly for ongoing interventions (every few weeks).</p>
<p>b. Interventions that will significantly and irreversibly compromise the physical and/or psychological integrity of patients should normally not be made by either supported decision-making approaches or by</p>	<p><u>Healthcare providers and caregivers:</u> Discuss less intrusive and holistic alternatives for addressing concerns of caregivers and others that give rise to requests for such interventions.</p>

<p>a substitute decision maker.^{xxv}</p>	
<p>c. Assisted suicide and euthanasia should never be authorized based on disabling conditions. Doing so sends the message that such conditions can be a ‘fate worse than death’ and undermines social solidarity and inclusion of persons with a disability.</p>	<p><u>Healthcare providers:</u> For patients with a disability requesting assisted suicide or euthanasia, as for any patient making such a request, screen for factors such as suggestibility, anxiety, depression, existential or spiritual distress, trauma, social isolation, stigma, sense of being a burden to others or lack of adequate supports.</p> <p>Explore and offer appropriate types of care (e.g., palliative care, which includes accompanying the patient through managing pain and symptoms, holistic approaches to alleviate loneliness, emotional, existential or spiritual distress).</p>
<p><i>4. Support caregivers and other decision-making supporters of patients: These persons should have sufficient resources and other supports for their role in promoting patients’ decision-making capabilities.</i></p>	<p><u>Healthcare providers:</u> Provide and discuss information with caregivers relevant to the decision and address their questions and concerns.</p> <p>Offer coaching, mentoring, and interventions to alleviate stress or distress of caregivers.</p> <p>Offer caregivers ethical and spiritual support as needed.</p> <p>Offer supports to mediate conflicts among family members or between patients and their caregivers regarding certain decisions.</p>
<p><i>5. Address lack of available decision-making supporters of persons who need them.</i></p>	<p><u>Faith and other communities:</u> Support socially isolated persons to develop friendships and other close, stable, and trusting relationships with members of your communities.</p>
<p><i>6. Advocate for policy change: Where supported decision-making approaches are not legally recognized, advocate for policy change.</i></p>	<p><u>All stakeholders:</u> Collaborate to advocate for policy change.</p> <p><u>Faith-based healthcare organizations:</u> Commit to leading in developing resources, policies, and exemplary practices in promoting decision-making capabilities of patients, including supported decision-making approaches.</p>

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Glossary of terms

Ableism is a bias that underlies certain attitudes or behaviours that disregard persons with impairments as being worth less than those without such impairments.

Accommodations, in the context of decision making, are a range of adaptations to enable persons to exercise their capabilities (e.g., allowing more time for decision making, adapting environments to reduce stress, addressing barriers of communicating, involving decision-making supporters).

Addiction refers broadly to a range of disorders associated with dependence on psychoactive substances or repetitive behaviours associated with reduced impulse control. We acknowledge that there is controversy regarding the classification of some or all of the latter so-called behaviours as an addiction.^{xxvi}

Assent is expressing or indicating one's will and preference verbally or non-verbally (e.g., through emotional cues, gestures or other behaviours). In ethics and law, persons deemed to lack decision-making competence or capacity might nonetheless be capable of assenting or dissenting to treatments.

Authentic values. Values can be authentic in both of these ways: (1) they are notions of what is good and worthwhile for enjoying a truly flourishing human life, which is what all humans intend or strive for; (2) they are what truly matters to a person; they form the core of a person's identity and are the source of goals or what a person hopes for in life. For an elaboration of these points, see Conn WE. Bernard Lonergan on value. *Thomist* 1976; 40(2): 243-257 and McCarthy MH. *Authenticity as self-transcendence: The enduring insights of Bernard Lonergan*. South Bend, IN, USA: Notre Dame University Press, 2015. For a different account based on the so-called "new natural law theory", see: John Finnis. *Natural law and natural rights*. Oxford: Oxford University Press, 1980 and 2011. Finnis lists, among his pre-moral principles of human existence or what he also calls "basic values" elsewhere: life, play, aesthetic experience, religion, practical reasonableness, knowledge and sociability. Similar possibilities for universal human aspirations and values have been surveyed by Dahlsgaard K, Peterson C, Seligman MEP. Shared virtue: The convergence of shared human strengths across cultures and history. *Review of General Psychology* 2005; 9(3): 203-213. The point that participants in the colloquium emphasized is that persons with profound intellectual and other cognitive disabilities can hold authentic values.

Autonomy has multiple meanings in philosophy, ethics, and the law. In this statement, we define autonomy as the exercise of decision-making capabilities that enables one to make decisions that align with one's goals and authentic values. Autonomy, understood in this way, is relational in at least three ways: A person's exercise of decision-making capabilities

depends on support from other persons in varying degrees. A person forms and lives out authentic values through interacting with others in their communities. Persons have a moral responsibility to pursue not only what is good for themselves but also the common good.^{xxvii}

Capability is a person's ability to function, which includes environmental and social conditions and supports that facilitate that functioning.

Caregiver, sometimes referred to as *carer*, is a term that connotes a range of persons giving care to patients, including companionship and support. These can be family members, friends or other persons who give care in a non-professional role. They might be trained or untrained. They usually are not remunerated financially for their caregiving.

Common good is "the sum total of social conditions which allow people, either as groups or as individuals, to reach their fulfilment more fully and more easily." It is different from the norm in utilitarian ethics, which aims to achieve the greatest good for the greatest number of people. See: Pontifical Council for Justice and Peace, *Compendium of the social doctrine of the Church* (2004): nos. 164-167.

Competence or capacity to make decisions. Recognition of a person's authority to make a decision, usually by demonstrating certain decision-making capabilities. Although these capabilities exist on a continuum, where on this continuum competence or capacity to make healthcare decisions is situated is normally defined by the law and determined by clinical judgment. In this colloquium, we discussed an approach (supported decision making) that does not entail a binary presence or absence in a person of competence or capacity to make decisions, and that is not necessarily conditional on a person independently demonstrating cognitive skills.

Compromised mental health encompasses a wide range of human experiences. On one end of this range are universal human distresses such as sadness, worry or fear in response to adversities of life. On the other are diagnosable mental health disorders. These are severe and persisting disturbances of experience, thought, mood or behaviour that can have a range of underlying causes, signs, and symptoms. The boundaries within the spectrum of mild, moderate or severe mental ill health experiences cannot always be delineated precisely. These distinctions are often based on their impact on the person's functioning or behaviour.^{xxviii}

Decision-making supporters are persons who are close to and know a patient well and, when needed, can reliably interpret the patient's goals and authentic values and enable the patient to decide on options that most align with these goals and values. They have an important role in supported decision-making approaches.

Disabilities are long-term impairments in persons or variations among persons that, in interacting with environmental and social barriers, limit their functioning and participating in society.

Health is harmony in and among the biological, psychological, environmental, social, and spiritual relations that contribute to overall human well-being. Illness is the experience of disharmony when one or more of these relations is disrupted or limited.^{xxix}

Health care includes a range of medical and other interventions that promote health, maintain or restore functioning, prevent disease or injury, and alleviate pain. The scope of health care is a controversial topic. Some limit it to interventions relating only to physical and mental health. This statement takes as a starting point the position that health includes well-being of the whole person, and hence, health care refers to holistic interventions that might also be needed to promote physical and mental health.

Healthcare providers are professionals trained to restore or promote human health, as defined above, e.g., physicians, nurses, pharmacists, physiotherapists, occupational therapists, dentists, audiologists, speech and language pathologists, psychologists, healthcare social workers, and providers of spiritual care.

Intellectual and developmental disabilities (IDD) are life-long challenges to cognitive, adaptive, and social skills that result from differences in neuro-psychological development before 18 years of age. These challenges vary in type and severity across a person's life phases and among persons with IDD. In this statement, IDD also includes Autism Spectrum Disorder. Although some persons living with an ASD do not meet cognitive and language impairment criteria for intellectual disability, their adaptive and social functioning can nevertheless be significantly impaired or under-developed.^{xxx} IDD is sometimes also referred to as *learning disabilities* or *developmental delays*.

Patient in this statement refers to a person receiving health care in any setting (e.g., at home, a congregate-living setting such as a group home or long-term care facility, a medical office or a hospital) and at any stage of an illness.

Progressive neuro-cognitive impairments are conditions associated with decline in more than one area of a person's cognitive or intellectual functioning (e.g., spatial orientation, short- and long-term memory, speech and language, problem solving, judgment, decision making) that become increasingly more severe over time, cannot be reversed, and eventually will lead to death.^{xxxi}

Substitute decision maker is a person (e.g., a family member, a legally appointed guardian) who authorizes decisions on behalf of a patient when this patient is assessed to lack decision-making competence or capacity. In bioethics and health law, there are alternative

terms for *substitute decision maker*, such as patient surrogate, proxy or representative, with varying roles and responsibilities stipulated for such persons.

Supported decision-making is an alternative approach to legal guardianship and other substitute decision-making arrangements for a person who, with the help of one or more decision-making supporters, is able to make decisions inter-dependently.^{xxxii}

Vulnerabilities in relation to the topic of this colloquium are factors that impede exercising decision-making capabilities. These can include cognitive impairments or certain disturbed mental states as well as environmental and social barriers, such as the lack of adequate supports.

About the IACB Colloquium

The International Association of Catholic Bioethics (IACB) is a community of bioethicists and providers of health and spiritual care.^{xxxiii} Founded in 2005, the IACB supports investigating and discussing emerging or controversial ethical issues in health care and biomedical research, especially those that concern the most vulnerable in society.^{xxxiv} These investigations and discussions engage with religious faith and are informed by the perspectives of affected persons; research; history; philosophical, ethical, and theological reflection. The primary work of the IACB is to organize colloquia where leading experts on a topic and members of the IACB community share ideas, develop positions, identify questions, and make recommendations for healthcare practices and policies.

The ninth international IACB colloquium was held in Quebec City, Canada, from June 16-21, 2019. Forty-eight participants from eight countries took part. We discussed promoting capabilities of persons who need support to make healthcare decisions. To focus our discussions, we considered four groups of patients: those with intellectual and developmental disabilities (e.g., Down syndrome, Autism Spectrum Disorder), progressive neuro-cognitive impairments (e.g., Alzheimer's disease, dementia due to Parkinson's disease), compromised mental health (e.g., depression, schizophrenia), addiction (e.g., to alcohol, substances) or some combination of these conditions.^{xxxv} We also discussed the important role of caregivers in supporting patients to make healthcare decisions.^{xxxvi}

Members of IACB's Academic Committee^{xxxvii} prepared two background papers that were offered to participants to read before the colloquium. During the colloquium, participants shared reflections from their own experiences as well as those of patients and caregivers regarding healthcare decision making.^{xxxviii} Keynote presenters^{xxxix} and other participants who presented shorter communications^{xl} proposed questions and case scenarios that small groups discussed. Moderators of those groups then reported main ideas to a Writing Group,

who are the authors of this consensus statement. Participants together reviewed and discussed parts of a draft of the statement throughout the colloquium. The Writing Group made amendments to the statement based on their suggestions. This and a subsequent draft of the statement were distributed after the colloquium so that participants could provide additional comments. Names of participants are listed to indicate their overall agreement with the content of this statement. It was not possible to resolve all relevant issues through this process. Questions for further thought and study are discussed in some of the endnotes.

References

ⁱ Convention on the rights of persons with disabilities. Geneva: United Nations; 2006.

Available at

https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf.

ⁱⁱ Thinkers from various traditions have elaborated a notion of inherent human dignity on different grounds. For example, in Western philosophy, Immanuel Kant. See Wood A. *Kant's ethical thought*. Cambridge, UK: Cambridge University Press, 1999. In East Asian thought, Confucius. See Zhang Q. Human dignity from a Confucian perspective: Toward a global constitutional principle. *Journal of Chinese Philosophy* 2002; 27(3): 299-330. Inherent human dignity is the basis of the United Nations' *Universal declaration of human rights*. Geneva: United Nations, 1948. Available online at: <https://www.un.org/en/universal-declaration-human-rights/index.html>. See the Preamble.

ⁱⁱⁱ Genesis 1.26: "Then God said, "Let us make humankind in our image, according to our likeness...." [NRSV]. See also Genesis 5.1-3; 9.6; Vatican Council II, *Pastoral constitution of the Church in the modern world: Gaudium et spes*. Vatican City, 1965, para. 19: "The root reason for human dignity lies in man's call to communion with God."

^{iv} Malleson T. Interdependency: The fourth existential insult to humanity. *Contemporary Political Theory* 2018; 17: 160-186.

^v Vanier J. *Becoming human*. Toronto: Anansi Press, 1998 and 2008.

^{vi} See glossary for definition of *common good*.

^{vii} Pontifical Council for Justice and Peace. *Compendium of the Social Doctrine of the Church*. Vatican City, 2004, para. 32: "The commandment of mutual love shows how to live in Christ the Trinitarian life within the Church, the Body of Christ, and how to transform history until it reaches its fulfilment in the heavenly Jerusalem."

^{viii} Office of the United Nations High Commissioner for Human Rights and the World Health Organization. *The right to health*. Geneva: OUNHCHR and WHO, 2008. Available online at: <https://www.ohchr.org/Documents/Publications/Factsheet31.pdf>.

^{ix} 1 Peter 4.10: “Like good stewards of the manifold grace of God, serve one another with whatever gift each of you has received.” [NRSV]. John Paul II, *Evangelium vitae*. Vatican City, 1995, para. 2: “[Life] remains a sacred reality entrusted to us, to be preserved with a sense of responsibility and brought to perfection in love and in the gift of ourselves to God and to our brothers and sisters.”

^x See glossary on *authentic values*.

^{xi} “The desire for God is written in the human heart, because man is created by God and for God; and God never ceases to draw man to himself. Only in God will he find the truth and happiness he never stops searching for.” *Catechism of the Catholic Church*. 2nd edition. Vatican City: Libreria Editrice Vaticana, 1997, para. 27.

^{xii} For one way of thinking about the importance of equity and restoration, see Sen A. Equality of what? *The Stanford University Tanner Lecture on Human Values*, May 22, 1979. Available online at: <https://tannerlectures.utah.edu/documents/a-to-z/s/sen80.pdf>. Reflecting on the reality of human inter-dependency, Eva Feder Kittay comments on the capabilities approach to justice as follows: “[A] theory of justice based on capabilities...does not address dependency head-on and therefore I would argue still needs supplementation with an ethic of care.” (Kittay EF. The ethics of care, dependence, and disability. *Ratio Juris* 2011; 24(1): 49-58. Her insight merits further exploration.

^{xiii} United States Conference of Catholic Bishops. *Economic justice for all*. Washington, D.C., 1997, 2009. For Christians, justice is not abstracted from love of neighbour. According to Pope Francis, “Our commitment does not consist exclusively in activities or programmes of promotion and assistance; what the Holy Spirit mobilizes is not an unruly activism, but above all an attentiveness which considers the other ‘in a certain sense as one with ourselves’. This loving attentiveness is the beginning of a true concern for their person which inspires me effectively to seek their good.” *Evangelii Gaudium*, para. 198.

^{xiv} Some participants in the colloquium held that assessments of legal capacity, which typically require patients to demonstrate certain cognitive skills such as understanding information and appreciating consequences, is a reflection of ableism (see glossary). It overlooks the decision-making capabilities of some patients with profound intellectual disabilities who hold authentic values, which can be interpreted reliably by close caregivers and other decision-making supports. These are relevant and significant for making treatment decisions regarding their health care. Further study of this issue is needed.

^{xv} See glossary on *autonomy*.

^{xvi} As an example of such a tool, see: Sullivan WF, Heng J, Bach M, Henze M, Kerzner L, Perry A, Vogt J. Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities. Toronto: Developmental Disabilities Primary Care

Program, Surrey Place, 2020. Available online at:
<https://ddprimarycare.surreyplace.ca/tools-2/>

^{xvii} Some participants in the colloquium noted that models for supported decision making are most advanced in regard to persons with intellectual and developmental disabilities. There is need for developing appropriate models for the specific needs and circumstances of other patient groups. Even in regard to persons with intellectual and developmental disabilities, there is a need for research to assess implementing supported decision-making approaches, especially in health care.

^{xviii} Some participants in the colloquium held the position that the role of patients in making decisions regarding their own health care should never be taken over entirely by a substitute decision maker, such as an appointed guardian. The *Report of the Special Rapporteur on the rights of persons with disabilities [Catalina Devandas-Aguilar] to the United Nations' Human Rights Council* (Geneva, Dec. 17, 2019) supports this position. Several jurisdictions in the world have changed or are revising their legal frameworks to recognize supported decision-making approaches in health care and other areas instead of resorting to substitute decision making.

^{xix} Participants in the colloquium noted that adults with intellectual and developmental disabilities are often not asked to participate in advance care planning, even at the end-of-life phase. There is limited research on this subject. Among elderly persons, early diagnosis of progressive neuro-cognitive impairments and compromised mental health aids advance care planning, but there is need for further research on ways to facilitate this.

^{xx} For example, healthcare providers can explore the legal possibilities for substitute decision makers to authorize a healthcare plan that allows patients and their decision-making supporter(s) to make day-to-day decisions in the context of that plan.

^{xxi} See footnote 26 above.

^{xxii} See glossary for a definition.

^{xxiii} Participants in the colloquium discussed and generally agreed with the helpfulness of the definition of best interests in the U.K.'s *Mental Capacity Act* to clarify responsibilities of substitute decision makers. According to this definition, the following should be considered: (1) the person's past and present wishes and feelings; (2) the beliefs and values that would be likely to influence the patient's decision if the patient had capacity; (3) the other factors that the patient would be likely to have considered. This approach does not require substitute decision makers to make a judgment about the decision the patient would have made if capable of doing so but to decide based on knowledge of the factors that might have influenced the patient if the patient had decision-making capability. See also Sulmasy DP, Snyder L. Substituted interests and best judgments: An integrated model of surrogate decision making. *Journal of the American Medical Association* 2010 (Nov 3); 304(17): 1946-7.

^{xxiv} See note 27 above.

^{xxv} There were participants who argued that decisions regarding such interventions should never be made without the patient's informed consent. An example of such interventions that was discussed in one of the small groups was non-therapeutic sterilization of adults with intellectual and developmental disabilities who are deemed not capable of giving consent to it.

^{xxvi} Grant JE, Chamberlain SR. Expanding the definition of addiction: DSM-5 vs. ICD-11. *CNS Spectr.* 2016 Aug;21(4):300-3.

^{xxvii} Ashley BM, deBlois JK, O'Rourke KD. *Health care ethics: A Catholic theological analysis.* 5th ed. Washington, D.C., U.S.A.: Georgetown University Press, 2006; p. 257.

^{xxviii} Sullivan WF, Heng J. Promoting mental health. IACB statement toward a shared medical and Christian ethical framework. *National Catholic Bioethics Quarterly* 2016 (Winter); 16(4): 663-676.

^{xxix} One way of describing these relations is proposed by Daniel P. Sulmasy in "A biopsychosocial-spiritual model for the care of patients at the end of life". *Gerontologist* 2002 Oct; 42 Spec. No. 3: 24-33. The importance of healing relationships in health care is highlighted in Sullivan WF, Heng J, De Bono C, Gleeson G, Goulding G, Jamieson C, et al. Healing Relationships and Transformations in Health Care. IACB Consensus Statement on Ethical Discernment and Practical Recommendations. *National Catholic Bioethics Quarterly* 2018 (Summer); 18(4): 319-327.

^{xxx} Sullivan WF, Heng J. People with intellectual and developmental disabilities and their families. An ethical framework and recommendations for health care practices and policies. *Journal of Religion and Society* 2015 (supplement 12): 107-134 and 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*. Another definition is that of the ICD-10: *International Statistical Classification of Disorders and Related Health Problems.* Tenth Edition (ICD-10). Geneva: World Health Organization; 1997.

^{xxxi} Sullivan WF, Heng J. Caring for and giving hope to persons with progressive cognitive impairments. *National Catholic Bioethics Quarterly* 2010 (Autumn); 10(3): 549-567. We use the term *progressive neuro-cognitive impairments* rather than *dementia* for several reasons. First, we want to avoid the pejorative sense that *dementia* has acquired in many languages and the hopelessness that this term often conveys to diagnosed individuals and their caregivers. See V. Hachinski, "Shifts in Thinking About Dementia," *JAMA* 300.18 (Nov. 12, 2008): 2172-73; Don I. Trachtenberg and John Q. Trojanowski, "Dementia: A Word to Be Forgotten," *Archives of Neurology* 65.5 (May 2008): 593-95. Second, by using the plural *impairments*, we want to signal that the conditions we were discussing involve more than one area of cognitive functioning. Third, we want to focus only on those cognitive impairments that are progressive, irreversible, and lead to death. See U. Guehne, S. Riedel-Heller, and M.C. Angermeyer, "Mortality in Dementia," *Neuroepidemiology* 25.3 (2005): 153-62. Thus the term *progressive neuro-cognitive impairments* does not include every type

of *dementia* described in the *International Statistical Classification of Disorders and Related Health Problems*. Tenth Edition (ICD-10). Geneva: World Health Organization; 1997 or the American Psychiatric Association's *Diagnostic and Statistical Manual*. 5th ed. Arlington, VA: American Psychiatric Association; 2013. The term *neuro-cognitive* acknowledges varying views on whether such impairments should be classified as mental and behavioural disorders or diseases of the nervous systems. ICD-10 classifies them among the former; the draft of ICD-11, among the latter.

^{xxxii} Sullivan WF, Heng J. Supporting adults with intellectual and developmental disabilities to participate in health care decision making. *Canadian Family Physician* 2018 (April); 64 (supplement 2): S32-S36. Sullivan WF, Heng J. People with intellectual and developmental disabilities and their families. An ethical framework and recommendations for health care practices and policies. *Journal of Religion and Society* 2015 (supplement 12): 107-134. Supported decision making is an approach that aligns with the United Nations' *Convention on the rights of persons with disabilities* declaration, article 12, which recognizes the right of persons with disabilities to legal capacity, i.e., to the authority to make their own decisions on an equal basis with others in society, with support as needed.

NOTES

^{xxxiii} The IACB is sponsored by the Order of Malta, a Catholic order with a mission to serve the sick and the poor. The Order is recognized by the United Nations as a sovereign state and by more than 100 other states.

^{xxxiv} See glossary for a definition of *vulnerability* as it relates to the topic of this colloquium.

^{xxxv} See glossary for definition of these terms, which can vary in terminology or meaning according to different classification schemes and local conventions.

^{xxxvi} See glossary for definitions of the terms *patient, caregiver, health, health care, and healthcare provider*.

^{xxxvii} These members were, in alphabetical order: John Heng, Cory Labrecque, Ursula Sottong, William F. Sullivan (chair), Paulina Taboada, Bernadette Tobin, and Jos Welie. Added to the Writing Group of this Committee were Christopher DeBono and Christine Jamieson. André Morin also provided helpful input.

^{xxxviii} For their personal accounts, we acknowledge with gratitude especially Audrey Cole, Gaie Haydon, Ursula Sottong, Paulina Taboada, and Kay Wilhelm.

^{xxxix} Keynote presenters were, in alphabetical order: Michael Bach and William F. Sullivan, Julian Hughes, Marie-Jo Thiel, Sander Welie, and Kay Wilhelm. Their contributions will be published separately in *Medicina y Ética* October 2020; 21(4).

^{xl} Presenters of brief communications were, in alphabetical order, Robert Boyko, Helen Butlin, Ian Casson, Audrey Cole, Pamela Cushing, Christopher DeBono, Kaya Duff, Jason Eberl, Christian Elia, Gill Goulding, Christine Jamieson, Nuala Kenny, Christina Lamb, Denis Larrivee, Andrew Mantulak, Hazel Markwell, Karen McNeil, Cecilia Moore, Paulina Taboada, Bernadette Tobin, Jos Welie, and Marleen Van Laethem.