Bioethics Outlook

Plunkett Centre for Ethics

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

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COVID-19:
its burdens on people with disabilities
&
the opportunities it offers for solidarity

In this issue

We publish a note from the Pontifical Academy for Life about the burdens that the pandemic has imposed not only on people with disabilities but also on their caregivers. Entitled *'Friendship with persons with disabilities and their carers: the beginnings of a new world'*, it draws on the work of the International Association of Catholic Bioethics, identifies key ethical concerns and offers a set of practical recommendations.

We give advance notice the next Plunkett Centre Webinar. Dr Steve Matthews and Dr Kirsten Challinor will lead a discussion entitled 'Aged Care: a safe place for home and work?

See the back page for details.

COVID-19: Human limitation and inter-dependency revealed

The COVID-19 pandemic has affected everyone. It has highlighted ways of living that, although already present, often remained undetected. Several documents of the Vatican COVID-19 Commission and the Pontifical Academy for Life have explored dimensions of the current crisis.[1]They jointly offer scientific and faith-based contributions that put us on the road toward a future in which the well-being of all will be promoted. This includes those among us who live with disabilities. While this pandemic starkly exposes lived experiences of uncertainty, limitation, andfrailty, persons with disabilities and their caregivers need and deserve special attention and supports because the pandemic has disproportionately impacted their lives in negative ways.

At the same time, as humans, our shared experiences of uncertainty, frailty, and limitation during this pandemic reveal our profound need for one another, and for God, in our search for well- being and meaning. As Pope Francis writes, *"The desire to live fully and experience new things is also felt by many young people with physical, mental and sensory disabilities. Even though they may not always be able to have the same experiences as others, they possess amazing resources and abilities that are often far above average. The Lord Jesus grants them other gifts, which the community is called to recognize and appreciate, so that they can discover his plan of love for each of them."*[2]

Disability refers to any impairment or physical and mental health condition that, in interacting with environmental and social factors, limits a person's functioning and participating in society.[3] Examples of disability include limited mobility, impaired vision or hearing, genetic and neurodevelopmental conditions such as Down syndrome or autistic spectrum disorder, acquiredbrain injury, dementia, and certain mental health conditions. One in six persons in the world, i.e.,over one billion, lives with some level of disability.[4] While the types and severity of disability vary, many persons with disabilities are among those at highest risk for severe illness and death due to COVID-19.[5] This is due not only to certain predisposing biological factors but also to several modifiable factors, such as unequal access to health care and other needed supports. Unlike other marginalized groups in society, the positive and negative impact of public health measures on persons with disabilities as a group, and on their caregivers, is significant and often not adequately being tracked.[6]

The COVID-19 pandemic, therefore, raises important ethical questions regarding our society's attitudes and behaviours toward people with disabilities. Pope Francis poignantly observes that,

"...the present pandemic has further highlighted the disparities and inequalities widespread in ourtime, particularly to the detriment of the most vulnerable. The virus, while it does not distinguish between people, has found, in its devastating path, great inequalities and discrimination. And it has only made them worse."[7]

Let us hope, and take steps to ensure, that the lessons we learn during the COVID-19 pandemic will lead us to focus on and rectify these failures. We can begin by being attentive to the experiences of persons with disabilities and their caregivers during this pandemic.

The experiences of persons with disabilities during COVID-19

While these experiences vary, overall, persons with disabilities who face barriers to maintaininggood health and accessing health care and other needed supports have fared far worse during this pandemic than those who do not experience similar health inequities.[8] Early on during the pandemic, the United Nations and the World Health Organization both called for disability- inclusive public health responses to COVID-19.[9]

Public health policies and interventions that target the general population during a pandemic often do not take into account the needs of persons with various disabilities. For instance, somepersons with sensory or cognitive impairments have found it difficult to get accessible information regarding preventing COVID-19 infections. Persons with limited mobility or sensory sensitivities have encountered barriers to being tested, vaccinated or treated in healthcare facilities. Public health authorities do not always direct those who implement policies and interventions to make reasonable adjustments for persons with disabilities, e.g., to provide accessible information, to adapt where and how tests and vaccines are delivered. Nor have policies restricting visits in hospitals and care homes, when other precautions are taken, been eased to enable family members and other caregivers to accompany persons with disabilities who need their support.

The synergistic effects of two or more health-related factors that result in increased rates of illness in a population has been called a "syndemic".[10] Some COVID-19 syndemic effects that have affected many persons with disabilities stem from reduced or lost supports that are vital formanaging daily life. Serious chronic health conditions, which are more prevalent among persons with certain disabilities than in the general population[11], remain unattended as healthcare systems shift resources to focus on preventing and treating COVID-19. [12] These chronic conditions deteriorate over time and can present as acute conditions when hospital care is sought, if available. Family and other caregivers of persons with disabilities have also been adversely affected by various pandemic-related changes (e.g., loss of employment,

reduced caregiving supports), which renders them less able to cope as caregivers.[13] In many parts of theworld, outbreaks or widespread infections have occurred where some persons with disabilities live in crowded conditions with poor hygiene because of poverty or long-term underfunding of certain congregate-living facilities.[14] Although many persons with disabilities are resilient[15], many others have also experienced the ill-effects of prolonged isolation in their homes during the pandemic, such as increased anxiety, loneliness, a sense of helplessness, despair, and domestic violence.[16] The longer these syndemic effects interact, the greater the risk will be that the physical, mental health and well-being of persons with disabilities will deteriorate, especially among those with the most severe disabilities and most easily compromised systems of support.

Even before the present pandemic, the healthcare decision-making capabilities of persons with intellectual and developmental disabilities and other cognitive impairments have too often beenoverlooked or not supported in healthcare systems.[17] This tendency is reinforced by a restrictedview of autonomy in certain prevalent bioethical and healthcare approaches, which places emphasis on independent decision making. Many persons with intellectual and developmental disabilities and other cognitive impairments, however, are capable of reaching responsible decisions regarding their health care if their needs are accommodated (e.g., offering more time,less stressful environments, alternative ways of communicating, and help from close and trustedcaregivers).[18] Persons with disabilities should be involved and supported as much as possible tomake advance care plans and healthcare decisions at all times, including during pandemics.

Regrettably, those among us with intellectual and developmental disabilities have also faced discrimination in decisions or policies regarding allocating ventilators and other scarce resourcesduring this pandemic because of a presumed poor quality of life.[19] This discrimination stems from an ableist bias, pervasive in healthcare systems, that regards disability negatively and perceives persons with disabilities as having lives that are less worth conserving than those of persons without such disabilities.

We must recognize, therefore, that the negative experiences of persons with disabilities during this pandemic do not only stem from the increased vulnerability that certain such persons have of being infected and developing serious COVID-19. They also stem from society's failure, generally, to value and include persons with disabilities when developing and implementing public health policies. In many countries, persons with disabilities and their families were not consulted on the development of these policies. This is first of all a symptom of their not being fully integrated in the community. In addition, as has been mentioned, the effects of such policies on the health and well-being of persons with disabilities as a group are seldom monitored. Yet, such persons are a significant proportion of the world's population, and one

that experience significant marginalization and health inequities.

Some ethical questions

How might prevailing medical and public health frameworks be adjusted to enable us to respond better to the needs of persons with disabilities globally during this, and future, pandemics?

Respect the dignity and equal worth of humans in considering the common good.

Public health ethics focuses on the public or common good. This should not be regarded as something apart from or opposed to beneficial goals that are inclusive of everyone. Nor should pursuit of the common good disproportionately burden anyone in society. During this pandemic,in many countries, the predominant ethical framework for practice and policy has been utilitarianand aimed at the greatest good for the greatest number in society. Such a framework has not served persons with disabilities and their families well. The specific needs of persons with disabilities have generally not been recognized among considerations of "the greatest good" in society. Also, being often marginalized, persons with disabilities are not included among "the greatest number" in society who are valued and who count. We need to challenge such ways ofthinking about the common good. While the common good is more than the good of any one person or the sum total of all goods, it must always pursue goals that are guided by respect for the dignity and equal worth of all persons. The common good ought to promote conditions for everyone's well-being.

Amidst changes in providing health care that are necessary for the common good during a pandemic, it is important not to abandon the goals of person-centered health care.[20] We should support public health frameworks that treat persons with disabilities and their caregivers as important contributors to policy making. We should promote accommodations for the specific needs of persons with disabilities to benefit from public health policies and interventions. We should involve such persons as much as possible in planning and making decisions regarding theirhealth care during a pandemic, with support from family and other trusted caregivers as needed.

Consider health and well-being comprehensively and relationally.

Public health frameworks can tend to over-medicalize responses to pandemics and focus on short-term goals without planning for the long term. We need public health frameworks for

pandemics that are guided by a holistic and relational understanding of human persons. Every human being consists of manifold and interacting biological, psychological, environmental, social and spiritual aspects. No human being can be reduced to simply one part or function of his or her relational being.

In public health, as in all health care, we must go beyond regarding disability solely in biological terms. We should support persons with disabilities and their families in coordinated and integrated ways across medical and other specialties, and various sectors of government and society. This will entail cooperation not just to prevent infection and respond to immediate acutehealth crises brought on by pandemics. It will also involve finding creative ways to attend to long- term rehabilitation needs, promote good health habits, manage ongoing health conditions other than COVID-19, foster resilience and mental health, maintain social and spiritual supports, and address health inequities.

Promote solidarity and a preferential option for the poor and vulnerable.

In a utilitarian approach to public health during a pandemic there can be a tendency to pit groupsagainst one another in competing for social recognition and scarce resources, e.g., persons withdisabilities against other vulnerable groups or some countries against others. We have witnessedthis sort of competition recently in allocating COVID-19 vaccines. We should question ableist andgroup bias when these influence the ways in which societies prioritize access to these and otherscarce healthcare resources during a pandemic. Overall, solidarity and a preferential option for the poor and vulnerable should guide allocation priorities.

During this pandemic, we have discovered that ethical questions regarding public health frameworks cannot be separated from ethical questions regarding how healthcare, economic, and political systems are organized. Generally, these tend to favour those most able to advocate for themselves, or who are powerful or privileged relative to others. Pope Francis's observation in his encyclical *Fratelli tutti* is relevant to the need for a world response to this pandemic based on a culture of loving solidarity, friendship, and cooperation: *"Local conflicts and disregard for the common good are exploited by the global economy in order to impose a single cultural model.This culture unifies the world, but divides persons and nations, for as society becomes ever moreglobalized, it makes us neighbours, but does not make us brothers. We are more alone than ever in an increasingly massified world that promotes individual interests and weakens the communitarian dimension of life."*[21]

Persons with disabilities are full members of a world community. When there are inequities

affecting distribution of vaccines and other healthcare resources among nations during a pandemic, however, persons with disabilities in disadvantaged parts of the world suffer doubly. They are disadvantaged within their countries, and they are disadvantaged in the world community. Thus, the pandemic will increase the gaps in care that pre-date the pandemic. To counteract this, we ought to develop public health frameworks based on solidarity and a preferential option for the poor and the vulnerable locally and globally. Recognizing and supporting persons who experience vulnerability, including disability, follows from human solidarity and our responsibilities.

Persons with disabilities: our teachers

As we wrote in our Note *Old Age: Our Future*, persons who are elderly and those with disabilities can teach us that human fragility, vulnerability, limitation, and lack of self-sufficiency place us all in need of God's healing and of dependence on one another.

This is the teaching authority of disability: need, vulnerability, and human limitation, which affectall of us, can open us to prayer to seek help, hope, and ultimate salvation. Even in the midst of our limitations, we can enjoy the blessings of life and love that we continue to receive. God is present and can reach and bless others through us even when our body, mind, and ability to communicate fail us. Addressing persons with disabilities, St. John Paul II reminds us, "*In your bodies and in your lives, dear brothers and sisters, you express an intense hope of redemption*."[22]

It is important to distinguish among different forms of vulnerability. In general, during a pandemicand at other times, we should promote health and prevent illness in ourselves and others as partof caring for the gift of life and being responsible for the common good. We should also addresssocietal injustices that result in increased vulnerability of disadvantaged groups to ill health and premature death. However, the denial or rejection of any limitation or vulnerability in the humancondition can often lead to societies that are uncaring or unjust. In such societies, persons with disabilities are rejected, regarded as the last to benefit from the common good or excluded entirely. In some societies, they are treated as disposable. We have witnessed some of these attitudes and behaviours during this pandemic.

The lessons that persons with disabilities can teach us, especially during this pandemic, are provocative. They challenge us to adopt a new perspective on the meaning of life. They invite us to accept inter-dependence, mutual accountability, and care for one another as a lifestyle and as away to promote the common good.

Forgetting or excluding persons with disabilities when considering the common good is a seriousproblem for all humanity and should never be the basis of public health frameworks. It communicates an unethical message that the vulnerable are unwelcome in society. It also treatspersons with disabilities as being of less value than others and unable to contribute to society. Such messages and actions affect not only persons with disabilities but also others such as embryonic humans, persons who suffer oppression or violence, migrants, and the homeless. There can only be hope for the present or future of a society when persons are welcomed when they are weak and in need of care, supported and loved as they change, and accepted as they grow frail.

The Christian faith teaches that vulnerability and limitation are inherent in the human condition.These can be a milieu of meaning and hope. This is what persons with disabilities can also teachus through the witness of their lives. Through his incarnation, Christ took on the limitations and vulnerability of the human condition and associated with the poorest, the weakest, the most marginalized and excluded in society.[23] The Suffering and Crucified One continues to live in solidarity with them during this pandemic and beyond. They are in the heart of God and central to the ministry of the entire people of God. The Church, therefore, has a mission to accompany,care and advocate for and with persons with disabilities.

Practical recommendations

A. We encourage all to advocate that persons with disabilities and their families be consulted indeveloping public health policies.

B. We urge authorities and researchers to monitor the effects of such policies and their implementation on the health and well-being of persons with disabilities and their families.

C. We call on Catholic healthcare organizations, who collectively comprise one of the world's most widespread and significant providers of healthcare and social support services, to show leadership in responding to the needs of persons with disabilities and their families during and after this pandemic.

D. As the world distributes COVID-19 vaccines, we recommend prioritizing not only those withincountries and communities who are at high risk of infection and severe illnesses, but also those,such as persons with disabilities, on whom generic public health measures impose disproportionate burdens (e.g., the loss of essential support services).

E. We support allocating healthcare resources during this pandemic according to policies and practices that do not discriminate against persons with disabilities solely on the basis of

their disability.

F. We urge global cooperation, “public-private” partnerships, and grassroots initiatives to improve vaccine uptake and overcome economic, political, and other barriers to distributing vaccines equitably within and among countries of the world.

G. Beyond this pandemic, as healthcare facilities begin to address the backlog of patients whosehealth needs have remained unattended during this pandemic, we urge developing measures toenhance access to health care of persons with disabilities so that they are not left behind in the queue for such services.

Hope for a new ethical world post-pandemic

The COVID-19 pandemic has provided humanity with an opportunity to reflect on how we regardand treat those who are most vulnerable in society. From this point of view, disability reveals ourinter-dependence and mutual responsibility for one another. We are all made in the image and
likeness of God. We all have equal dignity and worth. A world without borders, without prejudiceagainst people with disabilities, where none is left alone to deal with the challenges of personal survival—this is a world that we ought to strive to build. This is God’s Kingdom.

Christians are called to contribute to building such a world. Unfortunately, in Christian thought, disability has at times been identified as a consequence of original sin. However, Scripture revealsthat, from the beginning, human life, in all its dimensions, is marked by limitation and dependence. God created humanity (*Adam*) “from the dust of the ground” (*adamah*).[24] Nonetheless, “God saw everything that he had made, and indeed, it was very good.”[25]

The New Testament shows Jesus ushering in the Kingdom of God by tying himself to the ancientprophecies that proclaim salvation for those left behind by life. In the synagogue of Nazareth, after reading the words of Isaiah about the signs of salvation, Jesus proclaims that those words are where His Gospel begins.[26] In perfect harmony with this beginning, and with the witness provided by the actions of Jesus, the *eschaton*, the last days, will be marked by the presence of those who have been regarded as least of the members of the human family, whom Christ the King identifies with himself.[27]

Pope Francis comments: *“...almost everything in this world is passing away, like running water. But there are treasured realities that remain, like a precious stone in a strainer. What endures, what has value in life, what riches do not disappear? Surely these two: the Lord and our*

neighbour. These two riches do not disappear! These are the greatest goods these are to be loved".[28]

At the end of our lives and of human history, we will be judged on our love of our neighbour, especially the poor, the most vulnerable, and those regarded the least in the human family. Among these, in our day, are persons with disabilities. Let us resolve and take steps during and after this pandemic to ensure that, after the mud of the devastation of this pandemic has been strained away, we will build a better world—a world in which persons with disabilities are always valued, befriended, and loved.

Endnotes

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Plunkett Centre for Ethics Webinar

Tuesday 26 October 2021
10.00 – 11.15am

Join us online for a conversation

Aged Care:
a safe place for home and work?

Speakers

Dr Steve Matthews, Senior Research Fellow, Plunkett Centre, ACU & SVHA
&
Dr Kirsten Challinor, Lecturer in psychology, Australian Catholic University.

About the workshop

The recent Royal Commission into Aged Care uncovered disturbing patterns of sub-standard care and abuse. It pointed out that older people receiving aged care should be safe and free from abuse at all times.

A key recommendation of the Royal Commission was that we need to find ways to put into effect a person-first concept of care, that is, supportive care which addresses '…physical, social, psychological, cultural and spiritual needs…'

This webinar will address these issues by considering the ways in which an ethically-based conception of person-centred care interacts with the problem of aggression and violence in aged care institutions. In presupposing the idea of relational care – where care outcomes are dyadically generated – we will consider the perspective of carers, and of people living with dementia (PLWD).

Unless we consider these perspectives, the frequency and severity of aggression in aged care will continue at the current, alarmingly high rates.

To register please contact admin@plunkett.acu.edu.au