

## INVITED ARTICLE

# Ethics framework and recommendations to support capabilities of people with intellectual and developmental disabilities during pandemics

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## Abstract

A growing body of knowledge highlights the negative impact of the COVID-19 pandemic on the health and well-being of many people with intellectual and developmental disabilities (IDDs) and their caregivers. The underlying reasons are not only due to biomedical factors but also ethical issues. They stem from longstanding and pervasive structural injustices and negative social attitudes that continue to devalue people with IDD and that underlie certain clinical decisions and frameworks for public-health policies during this pandemic. Unless these fundamental ethical shortcomings are addressed, pandemic responses will continue to undermine the human rights and well-being of people with IDD. This paper proposes an ethics framing for policy and practices regarding clinical care and public health based on Martha Nussbaum's approach to Capability Theory. Such a framework can reorient healthcare professionals and healthcare systems to support the capabilities of people with IDD to protect, recover, and promote health and well-being. It could be applied during this pandemic and in planning for future pandemics. The paper presents some practical recommendations that follow from applying this framework.

## KEYWORDS

COVID-19, ethics, intellectual disability, health equity, health policy

## INTRODUCTION

Recent scoping reviews (Doody & Keenan, 2021; Taggart et al., 2022) have synthesized research on the impact of the COVID-19 pandemic on the health and overall well-being of people with IDD and their caregivers. Much of

this impact has been negative and shown to be disproportionate relative to the general population. The underlying reasons are due not only to biomedical factors but also ethical ones. Despite many recent positive steps toward recognizing the value and human rights of people with IDD, and policies to promote inclusion, these advances are fragile (Luckasson & Schalock, 2020). Negative social attitudes toward people with IDD and discriminatory structures and practices persist, sometimes covertly.

In this paper, we aim to discuss the ethical aspects of issues that have been described in recent publications on the impact of the COVID-19 pandemic. We highlight four

**Abbreviations:** CFS, Clinical Frailty Scale; CQC, Care Quality Commission; DNACPR, do not attempt cardiopulmonary resuscitation; IDD, intellectual and developmental disabilities; NICE, National Institute for Health and Care Excellence; UN, United Nations; WHO, World Health Organization.

key areas of ethical concern. People with IDD have a legitimate interest in protecting, restoring, and promoting their health and well-being during pandemics, just as all of us do. They often have unrecognized abilities and lack opportunities for this. We will discuss reasons why.

There are already other publications that discuss the need for a disability-rights framework or an equity framework to address the negative impacts of the COVID-19 pandemic on people with disabilities, including people with IDD, and other vulnerable groups in communities (Andrews et al., 2021; Chen & McNamara, 2020; Glover et al., 2020; Guidry-Grimes et al., 2020). This paper will add a critical ethical assessment of certain notions of the common good that underlie clinical decision-making and public-health policies. During pandemics, the focus of clinical decision-making and policy making shifts from the good of individuals to the common good. There is need for ethical framing for these policies and guidance for these practices. Such framing should emphasize that, during times of shared public-health crises, such as pandemics, addressing discrimination and inequities experienced by people with IDD *continue to be essential to promoting the common good*. We will propose such ethics framing, based on a version of Capability Theory, and give examples of policies and practices regarding pandemics that follow from this framework.

## Capability Theory

In political and legal philosophy, Nussbaum (2011)'s Capabilities Approach focuses on human dignity and communities promoting conditions and opportunities that are necessary for all members to attain their well-being. Nussbaum's version of Capability Theory asks, "What is each person able to do and to be?" (p. 18, 20). And what opportunities are available to the person in a community to choose and enact to be well and to flourish?

Nussbaum's approach to Capability Theory is similar to other approaches, such as those of Amartya Sen (1999) and Anand et al. (2020). Her approach is grounded on promoting human dignity and Central (i.e., threshold) Capabilities for *all* humans in a community: life; bodily health; bodily integrity; senses, imagination, and thought; emotions; practical reason; affiliation; other species; play; control over one's environment (pp. 33–34). Among these capabilities, she considers two to be fundamental because they organize and pervade the rest. These are affiliation and practical reason (p. 39). Although all 10 of Nussbaum's Central Capabilities have some bearing on the topic of this paper, we will focus on discussing affiliation and practical reason.

Affiliation includes having the opportunity to develop self-respect through a sense of belonging and being valued equally in a community. Affiliation entails that persons in a community are not subject to negative discrimination by others and have opportunities to share with others the common goods of a community, interact socially, and be engaged to participate in the community's life.

The capability of practical reason includes being able and having opportunities to make decisions according to the person's goals, values, and preferences in ways that promote a shared life with others in the community. It is not necessary to have independent skills for reasoning to be capable of practical reason. Such a capability can also be present in apprehending goals and values for one's life and community through affective cognition and in manifesting one's will non-verbally. This capability develops by interacting with and being supported by trusted loved ones. Almost all persons with IDD are capable, to some extent, of manifesting practical reason. They can and should be supported by other members of the community to do so and to have opportunities to realize and enhance such capability (Sullivan et al., 2021).

## Areas of ethical concern

Based on Nussbaum's Capabilities Approach, certain responses, or lack thereof, to the COVID-19 pandemic have been ethically problematic for people with IDD and for our communities. The key points are: (1) devaluing and lack of recognition of the inherent dignity of people with IDD continues to undermine their capability for affiliation. These have resulted in health inequities and discrimination in the health care of people with IDD, which have manifested and been exacerbated during the COVID-19 pandemic; (2) the same general failure to engage people with IDD, with supports as needed, to contribute to clinical decision-making regarding their own health is evident also in most communities failing to engage people with IDD and their caregivers in developing inclusive public-health policies and practices during the COVID-19 pandemic. This continues to undermine the capability for practical reason of people with IDD.

## Health inequities

Differences in health status and outcomes of healthcare procedures among members of a community could be due to vulnerabilities caused by non-preventable biological factors. The existence of such inequalities *per se* does not pose ethical questions. Health *inequities* or *disparities*,



however, stem from social, economic, environmental, and organizational factors. These can result in “differences in the opportunities groups have to achieve optimal health, leading to unfair and avoidable differences in health outcomes” (Weinstein, 2017). Relative to the general population, people with IDD are more likely to have unmet health needs, increased rates of avoidable hospitalization, and poorer experiences of health care (Lunsky et al., 2013; Menezes et al., 2021; Sheehan et al., 2016; Weise et al., 2021). Some premature deaths of people with IDD could have been prevented by timely and appropriate health care, according to reports from the UK (Heslop et al., 2014; Hosking et al., 2016) and Australia (Trollor et al., 2017). In both high- and low-income countries, people with IDD are also more likely than those without disabilities to experience poverty, inadequate housing, and social isolation. Such socioeconomic and environmental factors are associated with cascading adverse effects on health and well-being. They compound already existing challenges of people with IDD regarding access to services and quality of health care (Krahn & Fox, 2014).

The COVID-19 pandemic has exacerbated some of these inequities for people with disabilities, including IDD, and created other new ones (Baksh et al., 2021; Jeste et al., 2020; Jesus et al., 2021). For instance, periods of lockdown have exacerbated the social isolation and loneliness already experienced by many people with IDD and increased risk of further decreasing mental health and well-being. Even when lockdown measures were relaxed for the general population, some people with IDD in parts of the world were still required to “shield” at home and/or were confined to their rooms in congregate settings. Often, restrictive policies that were intended to mitigate the risk of infections did not attend to the need to adapt or increase supports. Even when restrictions eased and non-COVID-19 health services were being restored during certain stages of the pandemic, many people with IDD found themselves at the back of a long queue for those services.

There continues to be a gap between widespread affirmation in policies of the inherent dignity and equal worth people with disabilities, such as in the United Nations [UN] (2006)'s *Convention on the Rights of Persons with Disabilities*, and social structures and care practices that would promote opportunities for people with IDD in our communities to realize these rights. This is ethically problematic and should be addressed (Braveman et al., 2011). If this is an ethical obligation in relation to regular health care and public-health procedures in non-pandemic times, it should also be an essential part of preparing for and responding to pandemics (World Health Organization [WHO], 2020). Efforts should be made to mitigate the

compounding and cascading effects of such health inequities on people with IDD and other vulnerable groups during pandemics (Sabatello et al., 2020). Yet, the impact of public-health procedures during the pandemic on the health and well-being of people with IDD and their caregivers is also rarely monitored by governments and other authorities that are responsible for developing and implementing public-health policies.

Furthermore, as Abrams and Abbott (2020) have pointed out, references to “pre-existing [health] conditions” in policies and communications regarding risks of developing serious COVID-19 and of dying, rightly emphasize protecting vulnerable groups with those health conditions. But these references continue to miss the point that some of those conditions are due to health inequities, and socioeconomic and ecological factors, which should be addressed by communities.

### Pervasive negative attitudes regarding disabilities and discrimination

Taggart et al. (2022)'s scoping review found that there has been a “global failure across many HIC and low-to-middle income countries in protecting the human rights of people with an IDD during the COVID-19 pandemic.” Such rights follow from the inherent dignity and worth of all human beings. Inherent human dignity is recognized as the ethical foundation of the UN (2006)'s *Convention on the Rights of Persons with Disabilities*, which is binding on the 182 states to date that have ratified it.

Discrimination on the basis of disability is a violation of inherent human dignity and the equal worth of all humans. Yet, policies and practices have emerged during COVID-19 that did discriminate against people with IDD on the basis of their disability. For instance, in the UK, in the early stages of the pandemic, the “COVID-19 Rapid Guideline: Critical Care in Adults” or NG159 issued by the National Institute for Health and Care Excellence or NICE (2020) recommended using the Clinical Frailty Scale (CFS; Rockwood et al., 2005) to inform decisions regarding admission to intensive care. The CFS has not been validated for use with people with IDD or others who have lifelong physical or cognitive impairments. Moreover, certain criteria in the CFS (such as dependence on others for activities of daily living) had a potentially discriminatory effect on people with IDD, if assessed without being familiar with their capabilities or with the prejudice that their lives are not worth living. Sabatello et al. (2020) highlight that several states in the US also developed disability-based exclusion criteria for receiving life-saving interventions during the COVID-19

pandemic. Inclusion Europe (2020) reported similarly problematic guidelines in France, Italy, and Spain.

Even when challenges eventually led to changes in these and other discriminatory policies and guidelines, Haque and Stein (2020) have shown how decisions regarding health interventions made in the context of the COVID-19 pandemic can still be influenced by biases and negative attitudes toward people with disabilities that are pervasive among healthcare professionals. A poignant example that came to light in the UK and other countries during the COVID-19 pandemic is the practice of routinely applying 'do not attempt cardiopulmonary resuscitation' (DNACPR) orders to persons with disabilities, including persons with IDD. DNACPR decisions involving such persons and their families can sometimes be clinically and ethically appropriate. These decisions should not be made covertly, however, or based only on the person's disability. Between November 2020 and January 2021, in the UK, the Care Quality Commission (CQC)'s review found evidence that such discriminatory practices were occurring, even after the CQC and the National Health Service of England had raised critical concerns. In some instances, the existence of DNACPR orders also led to excessive delays in people with disabilities accessing regular health care (CQC, 2021).

### Failure to accommodate needs

The negative impacts of healthcare policies and practices on people with IDD during the COVID-19 pandemic could have been mitigated or avoided, in many instances, through reasonable adjustments to generic policies or usual procedures by adapting them to the needs and circumstances of people with IDD. Such adjustments are often needed to enable people with IDD to enjoy the same level and quality of health care as others in their community and the same opportunities to promote their health and well-being. For instance, people with IDD might need the support of other persons to assist with tasks of daily living, communicate, reach decisions, be resilient or participate as much as possible in the life of their community. Failure to make reasonable adjustments to care and public-health procedures harms people with IDD by disproportionately increasing the burden of those measures relative to others in the community. This is a matter of ethical concern with respect to ensuring distributive justice and equity for all members of the community in accordance with their needs. Because of the history of health inequities experienced by people with IDD, offering reasonable adjustments also is ethically justified by restorative justice, to make amends for past moral failures of a community. During the COVID-19 pandemic, however, it became evident that some public-health

measures were being implemented generically, without taking into account the specific needs of people with IDD and the potential for harm to them and their caregivers, whose support they require.

For instance, during various acute phases of the COVID-19 pandemic, many healthcare systems around the world prohibited family members and friends from visiting hospitalized patients or accompanying patients to medical appointments or to seek emergency care. While the rationale for such generic policies to reduce the risk of spreading infections can be understood, their disproportionately negative impact on many people with IDD was seldom considered or addressed. The absence of someone who is familiar with a person with IDD who is non-verbal and can support this person in communicating and reaching healthcare decisions can sometimes lead to denied or inappropriate health interventions (Heslop et al., 2014). The negative impacts of confinement at home and reduced social interactions on the physical and mental health and well-being of people with IDD can be significant (Lake et al., 2021; Rosencrans et al., 2021). These are greatly compounded for those who already have low levels of in-home supports or reduced supports because of the pandemic, lack the capability or means to benefit from communication technology and virtual care, or already experience compromised mental health and loneliness (Constantino et al., 2020; Courtenay & Perera, 2020).

### Narrow focus of clinical care and public-health policies and procedures during pandemics

Underlying some failures to make reasonable adjustments to generic public-health policies and usual clinical care practices for people with IDD is a tendency toward an overly narrow notion of health and the goals of care and public-health policies and procedures during pandemics. Often, these focus on merely preventing one possible illness. Luckasson and Schalock (2020) astutely observe that the COVID-19 pandemic "provides the impetus to consider the role that people and organizations play during times of crisis, to not only protect the health and safety of people with IDD, but also to continue to support their personal development, social inclusion, interpersonal relations, rights, and emotional well-being." While preventing infection, serious illness, and death due to an infectious disease are important goals for people with IDD and their loved ones, they are not their only goals. Weighing the goal of preventing COVID-19 against goals that relate to other aspects of human health and well-being, both in the short and long term, is a matter for ethical deliberation. People with IDD should be



involved in those deliberations as much as possible, both on the level of clinical decision making and on the level of planning and making policies regarding the whole community. People with IDD might, however, require and should receive the support of their families and others to participate in reaching responsible decisions personally and with their community.

### The need for adequate ethical framing for pandemic responses

The four areas of ethical concern discussed above are not new for people with IDD. But they have added poignancy regarding pandemics. During pandemics, the emphasis in clinical decision-making and public-health policies and procedures shifts from focus on the good of individuals to promoting the common good in facing a shared health crisis affecting the community.

The claim is often made, in this context, that public-health policies and procedures cannot possibly include or take into account the health interests of every individual or group in a community. Certain prevalent approaches to clinical decision-making and public-health policies and procedures follow from this claim: (a) the libertarian approach of balancing the interests of diverse, competing individuals and groups in a community by seeking *the least restrictive* public-health measures; (b) the communitarian approach in which the common good *takes precedence over* the interests of any individual or group, or (c) the utilitarian approach of seeking *the greatest good for the greatest number*. None of these approaches serves the well-being of people with IDD. In libertarian frameworks, the well-being of those who are unable independently to advocate for their health interests, or lack opportunities to do so, are overlooked. In communitarian frameworks, there is often little flexibility for reasonable adjustments to address unmet needs of those who require them on account of their disability. In utilitarian frameworks, the well-being of people with IDD and other minority groups are often excluded in considering the greatest good for the greatest number in communities. Or else, their well-being is significant only when it happens to coincide with the health interests of the majority in society.

Certain ethicists have argued for a disability-rights framework or equity framework to guide policies and practices during pandemics (Andrews et al., 2021; Chen & McNamara, 2020; Glover et al., 2020; Guidry-Grimes et al., 2020). As Jeffrey (2020) has argued, “[h]uman rights principles provide a framework for evaluating the ethical acceptability of public health measures that limit individual freedom. Principles of distributive justice, or equity, require that public health measures do not place unfair burdens on particular segments of the population.” (p. 495).

While defending and promoting disability rights are fundamentally important in the context of pandemics, such ethical framing needs to be supplemented and complemented. This framing implies, but does not make explicit, an appeal to the common good in health care, which is the basis of clinical decision-making and public-health policies and procedures that focus on the health of populations. A framing based on the common good can be drawn from Capability Theory, which emphasizes the inter-dependency among all members of a community and the ethical significance of promoting compassionate, supportive relationships, and solidarity among all.

## DISCUSSION

Capability Theory presupposes the importance of social relationships and interdependency among members of a community for flourishing human lives. It does not understand promoting the good of individuals to be opposed to promoting the good of a community or the common good. Rather, a community flourishes when the conditions are present for the well-being of every member of the community. This provides a response to the prevailing ethics frameworks underlying public health described above, all of which presuppose a bifurcation and opposition between promoting the good of individuals and the common good. When communities value and take care of those who are most in need of attention and support in our healthcare systems and communities, this brings out the best of everyone's humanity and contributes to the common good, as manifest in the flourishing of all.

Moreover, Capability Theory is holistic. It does not reduce human well-being and flourishing simply to promoting bodily health. It also provides a response to the prevailing ethics frameworks that focus too narrowly simply on preventing a single illness. It highlights the importance of a broader range of concerns for health and well-being, especially affiliation and promoting practical reason.

Capability Theory also can be interpreted to affirm the value of subsidiarity, which involves giving opportunities to those most affected by decisions to participate as much as possible in making those decisions and policies. Clinical decisions and public-health policies should not be made and implemented in a paternalistic or a top-down manner, when involvement of those affected is possible, even in the context of a health emergency or crisis. Importantly for people with IDD, Nussbaum criticizes certain political philosophies and governments that exclude people with disabilities when structuring societies and resources. She claims that, without their inclusion, solutions proposed for addressing unequal opportunities

available to certain members of a community will never truly address this problem.

Finally, Capability Theory broadens the ethical foundation for disability rights. Not only do those rights follow from respecting the inherent dignity and equal worth of all humans. They follow also from the human capacity for compassion and care for other members of one's community. This occurs when persons are aware of themselves as bearers of human capacities but, while seeking opportunities to realize and develop those capacities, are always "aspiring and vulnerable" (Nussbaum, 2001, p. 368). This awareness enables persons to *feel* empathy and compassion for, and kinship or solidarity with, others in the community, especially those who are worse off in terms of lacking those opportunities. Compassion and solidarity are made concrete by advocating for and taking action to attain distributive and restorative justice.

## RECOMMENDATIONS

The following are some practical recommendations that follow from applying an ethics framing for policy and practices regarding clinical care and public health based on Martha Nussbaum's approach to Capability Theory. Such a framework can reorient healthcare professionals and healthcare systems to support the capabilities of people with IDD to protect, recover, and promote health and well-being. It should be applied during this pandemic and in planning for future pandemics.

### Recommendations for all

- Recognize that ethics are fundamentally important to both regular health care and planning for and responding to pandemics. Take the initiative to foster and engage in public education and discussions on ethics in health care. Do not leave such efforts just to governments, public-health authorities, and the media.
- In public education and discussions, advocate for increased awareness of, and efforts to address systemically, the limited or reduced opportunities in health care affecting people with IDD and others in the community on account of the disadvantage, discrimination, and structural barriers such people experience. Recognize that equal opportunities and well-being *for all* in health care promotes the common good.

### Recommendations for policy-makers

- Planning for pandemics should be long-term and proactive. To mitigate risks and burdens to people with

IDD and other disadvantaged groups during pandemics, identify and address what unmet needs for supports such people have during times of non-crisis as a public health priority.

- Involve people with IDD, their families, and other carers at all stages of developing, implementing, and evaluating the impact of responses to pandemics. People with IDD are important stakeholders and have a role with others in promoting the common good. Offer opportunities and supports that are needed for people with IDD to participate meaningfully in pandemic responses.
- Support interdisciplinary inputs into planning responses to pandemics that seek the necessary balance between addressing a public-health threat and promoting overall human well-being.
- Support and rapidly access evaluations to adjust public-health procedures to reinforce positive impacts and correct negative impacts on people with IDD and other disadvantaged people in the community as part of public-health responsibility to promote the common good.

### For care providers

- Maintain holistic and person-centered approaches to care and implementing public health measures during pandemics. This is essential to, and not incompatible with, a concern for preventing infectious disease during pandemics:

- Recognize and attend to the complex and multi-dimensional needs of people with IDD by promoting their capabilities and offering supports needed to maintain health habits, manage co-morbid health conditions, and benefit from long-term rehabilitation after recovery from illness;

- Be educated about and make reasonable adjustments to usual care and in implementing generic public-health policies and procedures as needed by people with IDD;

- Recognize and attend especially to compromised mental health, past and present traumas, loneliness, and addictions; foster the capabilities of people with IDD to develop and maintain supportive relationships during pandemics.

- Promote decision-making capabilities of people with IDD, including advance care planning and decisions regarding public-health procedures.
- Support (through education, resources, and access to interdisciplinary teams) a key role for primary care providers in integrating various inputs and educating family and other caregivers of supports needed to ensure that people with IDD maintain health and well-being before, during, and after pandemics.



## CONCLUSION

A growing body of knowledge highlights the negative impact of the COVID-19 pandemic on the health and well-being of many people with IDD and their caregivers. The underlying reasons are not due only to biomedical factors but are ethical. They stem from longstanding and pervasive structural injustices and negative social attitudes that continue to devalue people with IDD and that underlie certain clinical decisions and frameworks for public-health policies during this pandemic.

During pandemics, the emphasis in clinical decision making and public-health policies and procedures shifts from focusing on the good of individuals to promoting the common good in facing a shared health crisis affecting the community. There is particular need for ethics framing emphasizing that, during times of shared public-health crises, defending human rights and addressing inequities experienced by people with IDD *continues to be essential to promoting the common good*.

In this paper, we have proposed such an ethics framework based on Capability Theory and shown how it supplements and bolsters frameworks based on disability rights and equity. We have also shown how such a framework challenges prevailing ethics frameworks in clinical decision making and public health during pandemics by emphasizing:

- a broader notion of the common good than protecting against a particular illness, but instead is based on a holistic understanding of human well-being and flourishing (e.g., promoting social relationships and participating in making decisions affecting oneself and one's community);
- inter-dependency among all members of a community and the importance of mutual support and compassionate care;
- the importance to the common good, therefore, of addressing matters not simply of distributive justice or promoting equity, but also restorative justice and giving priority in providing supports to those members of a community that have been, and continue to be, marginalized and excluded in health care because they lack such supports.

Unless fundamental ethical shortcomings underlying certain understandings of the common good in clinical decision-making and public-health policies and procedures are addressed, pandemic responses will continue to undermine the human rights and well-being of people with IDD. We propose the following as examples of practical recommendations for policy and practices that follow from lessons learned during the COVID-19

pandemics and from an ethics framework based on Capability Theory.

## CONFLICT OF INTEREST

None

## ETHICS STATEMENT

This paper does not involve participation of human subjects or methods requiring research ethics review.

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## REFERENCES

- Abrams, T., & Abbott, D. (2020). Disability, deadly discourse, and collectivity amid coronavirus (COVID-19). *Scandinavian Journal of Disability Research*, 22(1), 168–174. <https://doi.org/10.16993/sjdr.732>
- Anand, P., Ferrer, B., Gao, Q., Nogales, R., & Unterhalter, E. (2020). COVID-19 as a capability crisis: Using the capability framework to understand policy challenges. *Journal of Human Development and Capabilities*, 21(3), 293–299. <https://doi.org/10.1080/19452829.2020.1789079>
- Andrews, E. E., Ayers, K. B., Brown, K. S., Dunn, D. S., & Pilarski, C. R. (2021). Nobody is expendable: Medical rationing and disability justice during the COVID-19 pandemic. *The American Psychologist*, 76(3), 451–461. <https://doi.org/10.1037/amp0000709>
- Baksh, R. A., Pape, S. E., Smith, J., & Strydom, A. (2021). Understanding inequalities in COVID-19 outcomes following hospital admission for people with intellectual disability compared to the general population: A matched cohort study in the UK. *BMJ Open*, 11(10), e052482. <https://doi.org/10.1136/bmjopen-2021-052482>
- Braveman, P. A., Kumanyika, S., Fielding, J., Laveist, T., Borrell, L. N., Manderscheid, R., & Troutman, A. (2011). Health disparities and health equity: The issue is justice. *American Journal of Public Health*, 101(Suppl 1), S149–S155. <https://doi.org/10.2105/AJPH.2010.300062>
- Care Quality Commission [CQC] (2021). *Protect, respect, connect: Decisions about living and dying well during COVID-19*. London, UK: Care Quality Commission. Retrieved January 13, 2022, from [https://www.cqc.org.uk/sites/default/files/20210318\\_dnacpr\\_printer-version.pdf](https://www.cqc.org.uk/sites/default/files/20210318_dnacpr_printer-version.pdf).
- Chen, B., & McNamara, D. M. (2020). Disability discrimination, medical rationing and COVID-19. *Asian Bioethics Review*, 12(4), 1–8. <https://doi.org/10.1007/s41649-020-00147-x>
- Constantino, J. N., Sahin, M., Piven, J., Rodgers, R., & Tschida, J. (2020). The impact of COVID-19 on individuals with intellectual and developmental disabilities: Clinical and scientific priorities. *The American Journal of Psychiatry*, 177(11), 1091–1093. <https://doi.org/10.1176/appi.ajp.2020.20060780>
- Courtenay, K., & Perera, B. (2020). COVID-19 and people with intellectual disability: Impacts of a pandemic. *Irish Journal of*

- Psychological Medicine*, 37(3), 231–236. <https://doi.org/10.1017/ipm.2020.45>
- Doody, O., & Keenan, P. M. (2021). The reported effects of the COVID-19 pandemic on people with intellectual disability and their carers: A scoping review. *Annals of Medicine*, 53(1), 786–804. <https://doi.org/10.1080/07853890.2021.1922743>
- Glover, R. E., van Schalkwyk, M., Akl, E. A., Kristjansson, E., Lotfi, T., Petkovic, J., Petticrew, M. P., Pottie, K., Tugwell, P., & Welch, V. (2020). A framework for identifying and mitigating the equity harms of COVID-19 policy interventions. *Journal of Clinical Epidemiology*, 128, 35–48. <https://doi.org/10.1016/j.jclinepi.2020.06.004>
- Guidry-Grimes, L., Savin, K., Stramondo, J. A., Reynolds, J. M., Tsaplina, M., Burke, T. B., Ballantyne, A., Kittay, E. F., Stahl, D., Scully, J. L., Garland-Thomson, R., Tarzian, A., Dorfman, D., & Fins, J. J. (2020). Disability rights as a necessary framework for crisis standards of care and the future of health care. *The Hastings Center Report*, 50(3), 28–32. <https://doi.org/10.1002/hast.1128>
- Haque, O. S., & Stein, M. A. (2020). COVID-19 clinical bias, persons with disabilities, and human rights. *Health and Human Rights*, 22(2), 285–290.
- Heslop, P., Blair, P. S., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2014). The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: A population-based study. *Lancet*, 383(9920), 889–895. [https://doi.org/10.1016/S0140-6736\(13\)62026-7](https://doi.org/10.1016/S0140-6736(13)62026-7)
- Hosking, F. J., Carey, I. M., Shah, S. M., Harris, T., De Wilde, S., Beighton, C., & Cook, D. G. (2016). Mortality among adults with intellectual disability in England: Comparisons with the general population. *American Journal of Public Health*, 106(8), 1483–1490. <https://doi.org/10.2105/AJPH.2016.303240>
- Inclusion Europe (2020). Neglect and discrimination multiplied: How COVID-19 affected the rights of people with intellectual disabilities and their families. Retrieved January 13, 2022, from <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- Jeffrey, D. I. (2020). Relational ethical approaches to the COVID-19 pandemic. *Journal of Medical Ethics*, 46(8), 495–498. <https://doi.org/10.1136/medethics-2020-106264>
- Jeste, S., Hyde, C., Distefano, C., Halladay, A., Ray, S., Porath, M., Wilson, R. B., & Thurm, A. (2020). Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions. *Journal of Intellectual Disability Research*, 64(2), 825–833. <https://doi.org/10.1111/jir.12776>
- Jesus, T. S., Bhattacharjya, S., Papadimitriou, C., Bogdanova, Y., Bentley, J., Arango-Lasprilla, J. C., Kamalakannan, S., & The Refugee Empowerment Task Force International Networking Group of the American Congress of Rehabilitation Medicine. (2021). Lockdown-related disparities experienced by people with disabilities during the first wave of the COVID-19 pandemic: Scoping review with thematic analysis. *International Journal of Environmental Research and Public Health*, 18(12), 6178. <https://doi.org/10.3390/ijerph18126178>
- Krahn, G. L., & Fox, M. H. (2014). Health disparities of adults with intellectual disabilities: What do we know? What do we do? *Journal of Applied Research in Intellectual Disabilities*, 27(5), 431–446. <https://doi.org/10.1111/jar.12067>
- Lake, J. K., Jachyra, P., Volpe, T., Lunskey, Y., Magnacca, C., Marcinkiewicz, A., & Hamdani, Y. (2021). The wellbeing and mental health care experiences of adults with intellectual and developmental disabilities during COVID-19. *Journal of Mental Health Research in Intellectual Disabilities*, 14(3), 285–300. <https://doi.org/10.1080/19315864.2021.1892890>
- Luckasson, R., & Schalock, R. L. (2020). A balanced approach to decision-making in supporting people with IDD in extraordinarily challenging times. *Research in Developmental Disabilities*, 105, 103719. <https://doi.org/10.1016/j.ridd.2020.103719>
- Lunskey, Y., Klein-Geltink, J. E., & Yates, E. A. (Eds.). (2013). *Atlas on the primary care of adults with developmental disabilities in Ontario*. Institute for Clinical Evaluative Sciences and Centre for Addiction and Mental Health. Retrieved from <https://www.porticonetwork.ca/documents/38160/99698/Atlas+revised+2014/c2d68a41-ed3d-44dc-8a14-7f30e044c17e>
- Menezes, M., Robinson, M. F., Harkins, C., Sadikova, E., & Mazurek, M. O. (2021). Unmet health care needs and health care quality in youth with autism spectrum disorder with and without intellectual disability. *Autism*, 25(8), 2199–2208. <https://doi.org/10.1177/13623613211014721>
- NICE (2020). COVID-19 rapid guideline: Critical care in adults. NICE guideline N159. Retrieved January 13, 2022, from <http://www.nice.org.uk/guidance/ng159>.
- Nussbaum, M. (2001). *Upheavals of thought: The intelligence of emotions*. Cambridge University Press.
- Nussbaum, M. (2011). *Creating capabilities: The human development approach*. Belknap Press of Harvard University Press.
- Rockwood, K., Song, X., MacKnight, C., Bergman, H., Hogan, D. B., McDowell, I., & Mitnitski, A. (2005). A global clinical measure of fitness and frailty in elderly people. *CMAJ*, 173(5), 489–495.
- Rosencrans, M., Arango, P., Sabat, C., Buck, A., Brown, C., Tenorio, M., & Witwer, A. (2021). The impact of the COVID-19 pandemic on the health, wellbeing, and access to services of people with intellectual and developmental disabilities. *Research in Developmental Disabilities*, 114, 103985. <https://doi.org/10.1016/j.ridd.2021.103985>
- Sabatello, M., Burke, T. B., McDonald, K. E., & Appelbaum, P. S. (2020). Disability, ethics, and health care in the COVID-19 pandemic. *American Journal of Public Health*, 110(10), 1523–1527. <https://doi.org/10.2105/AJPH.2020.305837>
- Sen, A. (1999). *Development as freedom*. Alfred A. Knopf.
- Sheehan, R., Gandesha, A., Hassiotis, A., Gallagher, P., Burnell, M., Jones, G., Kerr, M., Hall, I., Chaplin, R., & Crawford, M. J. (2016). An audit of the quality of inpatient care for adults with learning disability in the UK. *BMJ Open*, 6(4), e010480. <https://doi.org/10.1136/bmjopen-2015-010480>
- Sullivan, W. F., Heng, J., & Bach, M. (2021). Promoting decision making capabilities in the healthcare of adults with intellectual and developmental disabilities: Ethics and practice. In I. Khemka & L. Hickson (Eds.), *Decision making by individuals with intellectual disabilities: Integrating research into practice* (pp. 47–64). Springer Nature.
- Taggart, L., Mulhall, P., Kelly, R., Trip, H., Sullivan, W. F., & Wallén, E. F. (2022). Preventing, mitigating, and managing future pandemics for people with an intellectual and developmental disability - learnings from COVID-19: A scoping review. *Journal of Policy and Practice in Intellectual Disabilities*, 19(1), 4–34. <https://doi.org/10.1111/jppi.12408>
- Trollor, J., Srasuebku, P., Xu, H., & Howlett, S. (2017). Cause of death and potentially avoidable deaths in Australian adults with





- intellectual disability using retrospective linked data. *BMJ Open*, 7(2), e013489. <https://doi.org/10.1136/bmjopen-2016-013489>
- United Nations [UN]. (2006). *Convention on the rights of persons with disabilities*. Geneva. Retrieved January 13, 2022, from <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- Weinstein, J. N. (2017). *Communities in action: Pathways to health equity*. Washington, D.C.: National Academies Press. Retrieved January 13, 2022, from <https://www.ncbi.nlm.nih.gov/books/NBK425845/>
- Weise, J. C., Srasuebkul, P., & Trollor, J. N. (2021). Potentially preventable hospitalisations of people with intellectual disability in New South Wales. *The Medical Journal of Australia*, 215(1), 31–36. <https://doi.org/10.5694/mja2.51088>
- World Health Organization [WHO] (2020). Policy brief: A disability-inclusive response to COVID-19. Retrieved January 13, 2022, from [https://www.un.org/en/content/disabilitystrategy/assets/documentation/UN\\_Disability\\_Inclusion\\_Strategy\\_english.pdf](https://www.un.org/en/content/disabilitystrategy/assets/documentation/UN_Disability_Inclusion_Strategy_english.pdf).

**How to cite this article:** Sullivan, W. F., Björne, P., Heng, J., & Northway, R. (2022). Ethics framework and recommendations to support capabilities of people with intellectual and developmental disabilities during pandemics. *Journal of Policy and Practice in Intellectual Disabilities*, 19(1), 116–124. <https://doi.org/10.1111/jppi.12413>