



Aging and End of Life Recommendations

Recent advances in science and healthcare have seen the life expectancy of people with intellectual and developmental disabilities (I/DD) increase over time. People with I/DD have often had a shorter life expectancy than their nondisabled peers due to a variety of factors, including institutionalization, lack of research on health outcomes, and disparities in preventive care.^{1 23} The healthcare industry faces new considerations for this growing aging population with I/DD.⁴

A gap analysis was conducted to better understand the healthcare inequities faced by individuals with disabilities facing aging and end of life. A gap analysis is a tool that is used to help investigate and create a plan to fix a problem or issue, utilizing a 4-step process to identify the current state of an issue, identify the ideal future state, find the gaps between the two, and then create a plan to close those gaps. Based on the gap analysis, recommendations were created to serve as a tool to reduce the disparities in aging and end-of-life care.

These recommendations emphasize the need for more training and introspection into the implicit biases regarding disability that are innate in our healthcare system, and the ways in which they can be mitigated. They also provide practical approaches for ensuring that utilization of lifesaving measures or withdrawal end-of-life care are based on actual patient preference and wishes, rather than a presumed understanding of the patient's quality of life.

¹ In 2017, as compared to adults with no intellectual or developmental disability, adults with intellectual disabilities lived 12 fewer years; with Down syndrome, 18 fewer years; and with cerebral palsy, 23 fewer years. Source: DD Age at Death Data Tracker. Syracuse University. (<https://asi.syr.edu/idd-age-at-death-data-tracker/>).

² Iezzoni LI, Rao SR, Ressler J, Bolcic-Jankovic D, Agaronnik ND, Donelan K, Lagu T, Campbell EG. Physicians' Perceptions Of People With Disability And Their Health Care. *Health Aff (Millwood)*. 2021 Feb;40(2):297-306. doi: 10.1377/hlthaff.2020.01452. PMID: 33523739; PMCID: PMC8722582. (<https://pubmed.ncbi.nlm.nih.gov/33523739/>).

³ Krahn GL, Fox MH. Health disparities of adults with intellectual disabilities: what do we know? What do we do? *J Appl Res Intellect Disabil*. 2014 Sep;27(5):431-46. doi: 10.1111/jar.12067. Epub 2013 Jul 31. PMID: 23913632; PMCID: PMC4475843.

⁴ Scott D. Landes et al., "Evidence of Continued Reduction in the Age-at-Death Disparity Between Adults With and Without Intellectual and/or Developmental Disabilities," *Journal of Applied Research in Intellectual Disabilities* 34, no. 3 (2021): 916-20. (<https://onlinelibrary.wiley.com/doi/10.1111/jar.12840>).

The recommendations are summarized as follows:

1. Ensure adequate training for healthcare providers in aging and end of life care for individuals with I/DD (disabilities)
2. Ensure that aging and end-of-life planning is person-centered and always directly includes the input of the person with a disability, using relevant accommodations as needed. This should apply regardless of whether or not an individual has an assigned legal guardian.
3. Raise awareness regarding bias and diagnostic overshadowing that may inappropriately impact decisions regarding aging and end-of-life care.
4. Encourage increased research regarding the aging and end-of-life care of people with I/DD and include this population in current aging and end-of-life research

Recommendation #1: Improved Healthcare Professional Training

In a recent study, only 40.7% of Physicians were ‘very confident’ about their ability to provide the same quality of care to patients with disabilities as non-disabled patients.⁵ The lack of confidence among the majority of physicians is a multifactorial issue which includes inadequate education and training among healthcare professionals with regard to people with I/DD. More specifically, palliative care staff have stated they have a “lack of experience and low levels of confidence” in caring for individuals with an Intellectual Disability during end-of-life.

Therefore, The Center for Dignity in Healthcare for People with Disabilities recommends that medical professionals be required to take additional training that emphasizes relationship and person-centered care approaches at the end of life.

Recommendation #2: A Person-Centered Approach to Decision Making

Research demonstrates that the voices of people with disabilities are sometimes not included in their own end-of-life decisions. In one study, adult respondents with an intellectual disability reported low levels of involvement in care and even unawareness of approaching death, at rates lower than in the general population.⁶ The gap analysis highlighted that because death and dying are generally taboo in our society, conversations that would clarify the wishes of the aging or ill person often go undiscussed. The gap analysis further illuminated that the lack of

⁵ Iezzoni LI, Rao SR, Ressler J, Bolcic-Jankovic D, Agaronnik ND, Donelan K, Lagu T, Campbell EG. Physicians' Perceptions Of People With Disability And Their Health Care. *Health Aff (Millwood)*. 2021 Feb;40(2):297-306. doi: 10.1377/hlthaff.2020.01452. PMID: 33523739; PMCID: PMC8722582. (<https://pubmed.ncbi.nlm.nih.gov/33523739/>).

⁶ Hunt K, Bernal J, Worth R, Shearn J, Jarvis P, Jones E, Lowe K, Madden P, Barr O, Forrester-Jones R, Kroll T, McCarron M, Read S, Todd S. End-of-life care in intellectual disability: a retrospective cross-sectional study. *BMJ Support Palliat Care*. 2020 Dec;10(4):469-477. doi: 10.1136/bmjspcare-2019-001985. Epub 2019 Oct 16. PMID: 31619439. (<https://pubmed.ncbi.nlm.nih.gov/31619439/>).

willingness to discuss the topics of death and dying are even more exacerbated when communicating with people with I/DD. However, it is imperative that people with I/DD are included in the planning of their care at the end of their lives.

Some adults with disabilities face insurmountable communication challenges that preclude them from expressing their end of life wishes to caregivers or guardians. Finding appropriate accommodations, specifically regarding communication, is necessary to ensure a person is able to embrace their preferred quality of life in their end-of-life care.

Therefore, The Center for Dignity in Healthcare for People with Disabilities recommends that all medical professionals engage in care that emphasizes relationship and person-centered care approaches at the end of life.

Unfortunately, guardianship laws are not always helpful in clarifying how decisions are made in some cases and who has the final authority to make them. We discuss guardianship and the decision-making and communication spectrum further in Appendix A. While we acknowledge that there is a need for improved public policy surrounding guardianship, it is essential that people with I/DD are included in the decision-making process, utilizing the patient-centered approach, regardless of guardianship status.

Recommendation #3: Improve Diagnosis and Treatment at End of Life

The phenomenon of “diagnostic overshadowing” is an issue for almost all people with I/DD throughout their life. Diagnostic overshadowing is when a physician misdiagnoses or under-diagnoses a person’s medical problem because of “a judgment bias where health care professionals mistakenly attribute clinical manifestations of physical illness (eg, pain, tachycardia, hypertension) to manifestations associated with a pre-existing mental illness.”⁷ People with I/DD are stigmatized and have experiences of discrimination that cause them to receive poorer quality healthcare because the symptoms of their ailments are mistakenly attributed to their disability. Especially at the end of life, diagnostic overshadowing can cause a person with I/DD to receive less than adequate palliative care.

Therefore, The Center for Dignity in Healthcare for People with Disabilities recommends that palliative care professionals should be specifically trained to recognize the symptoms of people with I/DD and how they manifest in ways that may be different from the general, non-disabled population, but that are not attributable to their disability.

⁷ Molloy, R., Munro, I. & Pope, N. (2021b). Understanding the experience of diagnostic overshadowing associated with severe mental illness from the consumer and health professional perspective: A qualitative systemic review protocol. *JBI Evidence Synthesis*, 19 (6), 1362-1368. (<https://doi.org/10.11124/JBIES020-00244>).

Recommendation #4: Address Gaps in Information and Improve Research

Insufficient data exists to support evidence-based clinical practice in regard to the health and wellness of aging adults with I/DD. Specifically, there is a need for future studies that use prospective, longitudinal methods, especially to identify the nature of age-related changes for people with I/DD in behavior, cognition and neurobiology.

Relatedly, there is a gap in social scientific knowledge pertaining to how people with I/DD are able to exercise their self-determination as they age.⁸ This is especially true for decisions about end-of-life care. Research has not yet shown the scope of the problem of people with I/DD not being given the chance to express their end-of-life wishes. It is largely unknown the extent to which people with I/DD do or do not participate in their own end-of-life decisions on a systemic level.

Therefore, The Center for Dignity suggests more research is needed to illuminate how people with I/DD are involved with their healthcare decisions and end-of-life care as they age.

Summary and Additional Recommendations

We recommend that health care providers have a policy in place to ensure that people with disabilities are able to participate in making decisions about their care to the maximum extent possible, especially as they age. Physicians need to be aware that direct support professionals may or may not know the individual with a disability who is under their care and so additional effort may be needed to identify someone able to assist a patient with I/DD to make decisions about their end-of-life care.

There is a pressing need to better understand the challenges that arise for aging and end of life care when a person with I/DD is under guardianship.⁹ To meet this need, we have provided two case studies and expanded on the recommendations regarding guardianship and surrogate decision-making in Appendix A.

Conclusion

We recommend training and education for health care professionals focused on caring for individuals with intellectual and developmental disabilities who are aging and/or facing end-of-life decisions. Even health provider specialty groups have very little to no information included in their conferences, trainings, and information posted on their websites.

⁸ Vicente E, Mumbardó-Adam C, Guillén VM, Coma-Roselló T, Bravo-Álvarez MÁ, Sánchez S. Self-Determination in People with Intellectual Disability: The Mediating Role of Opportunities. *Int J Environ Res Public Health*. 2020 Aug 26;17(17):6201. doi: 10.3390/ijerph17176201. PMID: 32859080; PMCID: PMC7503306. (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7503306/>).

⁹ The Center for Dignity acknowledges that guardianship can be problematic for people with I/DD of all ages, but we have chosen to focus these recommendations on end-of-life care and aging.

Those groups we approached, including the American Academy of Hospice and Palliative Medicine, were very open to having presentations on these topics and collaborating on future training and education endeavors. We received the same positive response from clinicians in the field who shared their experiences and welcomed opportunities for more training and education for health care providers.

Appendix A

Guardianship and Decision-Making

There is a pressing need to better understand the challenges that arise for aging and end of life care when a person with I/DD is under guardianship.¹⁰ To meet this need, we have provided two case studies and expanded on the above recommendations to address concerns around guardianship and surrogate decision-making.

Case Study #1: Guardianship and Sarah McSweeney

Background: On April 21, 2020, a patient who we will refer to by the name Sarah McSweeney to preserve anonymity arrived in the emergency room with a high fever. Tests showed she did not have COVID-19, but in the hospital she had episodes of aspiration pneumonia, where fluid backed up into her lungs while she was being fed. Prior to the emergency room visit, McSweeney had been living in a group home. She had multiple disabilities— she was quadriplegic, and she couldn't swallow, and although she could not speak words, the people who worked with her could understand her by her sounds and facial expressions.

Case Presented: Sarah McSweeney's case was complex as a patient whose wishes were not ascertainable through direct communication. These disabilities caused a practical problem for the medical team attending to her: How would they know what Sarah McSweeney wanted? The medical team questioned her quality of life prior to her hospital visit. Doctors discussed the possibility of her being intubated and letting the lung rest, giving her time to heal and letting the antibiotics work.

Outcome: But McSweeney was not moved back to the ICU and was not put on a ventilator. She died on May 10 of severe sepsis because of aspiration pneumonia.

Considerations: Sarah McSweeney had caregivers from the group home where she had lived for nearly fifteen years. They knew her wishes and were much more experienced in interpreting her nonverbal communication than the members of her medical team. But the medical team only worked with them intermittently and, when it came time to decide whether McSweeney should be placed on ventilation, the medical team disregarded McSweeney's previously expressed wishes, as well as her guardians' pleas. As a result, McSweeney died a premature death, riddled with unnecessary anguish and suffering.

¹⁰ The Center for Dignity acknowledges that guardianship is problematic for people with I/DD of all ages, but we have chosen to focus these recommendations on end-of-life care and aging.

Conclusion: 1. McSweeney's story highlights the lack of understanding of guardianship in the healthcare system. 2. McSweeney's story has become a prominent example of how disability discrimination persists in health care facilities.

Recommendations: This case study exemplifies the discrepancy that can occur regarding the value placed on quality of life between patients and physicians. Patients, especially those with disabilities, often have different metrics for what they believe is a life worth living. Physicians tend to hold biases toward disability and to believe that having a disability always leads to low quality of life. Implicit biases can place physicians and patients in an adversarial role and prevent utilization of a person-centered approach to palliative care.

Case Study #2: Baby Doe

A baby was born with Down Syndrome and a subsequent heart condition that required surgery in 1982. The parents of Baby Doe refused the surgery on the basis of the child having Down Syndrome. A guardian was appointed by the hospital and the courts later ruled in favor of the parents. The baby later died as a result of not having the surgery.

Medical/Bioethical Protocols for Surrogate Decision Making

The Baby Doe case and subsequent court rulings and legislation established that hospitals must provide life- saving treatment to disabled infants, irrespective of parents' wishes, or risk losing federal funding. Exceptions exist for infants that are in a permanent coma, terminally ill, or if the treatment itself is "inhumane."

The "substituted judgment standard" of surrogate decision-making applies when a person once had decision-making capacity and lost it, but information is known about their values and/or wishes.¹¹ This standard requires a surrogate who knew the patient when they had capacity to make a decision based on knowledge of what the patient values and a projection of what the patient would want if they were able to decide for themselves.

The "best interests standard" of surrogate decision-making applies when a person never has had decision-making capacity *or* no information is known about their previous values and/or wishes when they did have capacity.¹² This standard requires a surrogate to make a decision based on a judgment of what is in the patient's best interest, including and especially considering their quality of life. These judgements are based on how a "reasonable person" would assess the patient's best interests, not any prediction about what the patient themselves would want. The Baby Doe rules incorporate this standard.

¹¹ Torke AM, Alexander GC, Lantos J. Substituted judgment: the limitations of autonomy in surrogate decision making. *J Gen Intern Med.* 2008 Sep;23(9):1514-7. doi: 10.1007/s11606-008-0688-8. Epub 2008 Jul 10. PMID: 18618201; PMCID: PMC2518005.

(https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2518005/pdf/11606_2008_Article_688.pdf).

¹² Kapp, M. B. (2010). Medical decision-making for incapacitated elders: A "therapeutic interests" standard. *International Journal of Law and Psychiatry*, 33, 369–74. doi:10.1016/j.ijlp.2010.09.008.

Recommendations: To avoid bias, the surrogate should not incorporate his/her particular views or values but rely on either: 1) information about the patient's previous wishes or 2) judgements that would be endorsed by an objective third party (the reasonable person).

Why these protocols do not account for the particularity of guardianship

Neither the substituted judgment standard nor the best interest standard incorporates the currently expressed wishes of people who may not have full decision-making capacity but do have views about how their own treatment should be provided. Many people with guardians have preferences, values, or beliefs regarding their own treatment, even if they are judged to not have the ability to make complex medical decisions on their own. In these cases, there needs to be a standard that incorporates the person's preferences, values, or beliefs into the decision-making process of the surrogate. Current standards are only based on 1) information about the patient's previous wishes or 2) judgements that would be endorsed by an objective third party; they do not give any weight to a patient's *current* wishes if that patient has been deemed to not have capacity, as in guardianship arrangements.

There are numerous issues regarding the patient-guardian relationship that are ill-defined and for which there is no process to resolve disputes. There is no clear consensus on how clinicians should handle disagreements between a person with a disability and their guardian. There needs to be a mechanism in place to ensure that the self-advocate's wishes are heard, even if the guardian disagrees with that course of action. Too often, patients who have been assigned guardians have little recourse in changing their guardians or requesting that the probate court re-evaluate their case to determine if they still require guardianship. This is out of the scope of medical practice, but no legal protocols are in place to address these issues.

Recommendations:

The substituted judgment standard and best interest standard may serve as critical safeguards to ensure that people with disabilities do not experience medical neglect or abuse at the hands of caregivers. However, an alternative standard must be developed and utilized that focuses on incorporating the expressed wishes of people with disabilities into the decision-making process—even if they are deemed “incompetent.” What may appear to be objective or reasonable to a typical, mainstream, physician or judge is in reality, biased by an ableist culture, even if that third party is supposed to be using an “objective” or “reasonable” standard of measurement. Therefore, it is essential that the individual patient be able to make their own judgment about their quality of life rather than a third party because of the ways in which our culture largely assumes that disability inevitably and profoundly diminishes a person's quality of life.

