

Introduction - Module #1

Welcome and thank you for participating in this research project. My name is Martin Viola and I am one of the Principal Investigators of this study.

Our goal today is to give healthcare workers such as yourself resources and tools to address the needs of patients with intellectual and developmental disabilities as they near death. This information is based on best practices collected from the scientific literature as well as interviews we've done with stakeholders from the disability community. We hope that providing this information will stimulate discussions about how to improve care at the end-of-life, and we look forward to hearing your thoughts and feelings about this presentation. Before we begin, we would like to state that this content does not constitute medical or other professional advice, and is solely for educational purposes. Without further ado, let's get started.

What are developmental disabilities?

Developmental disabilities are chronic conditions arising in childhood that lead to impairment in areas of living like mobility, language, or independent living.¹ Examples of developmental disabilities include cerebral palsy, impairments in vision or hearing, and autism spectrum disorder. One specific type of developmental disability is intellectual disability. This refers to significant impairments in both intellectual functioning and adaptive functioning.²

Because of this broad definition, people with developmental disabilities are a very diverse group. Some patients who have developmental disabilities also have intellectual disabilities; some do not. Levels and areas of impairment, as well as the kind of assistance needed, differ greatly from person to person.

In New York State, roughly 2% of Medicaid recipients had an intellectual or developmental disability.³ Worldwide, prevalence rates of intellectual disability are approximately 1%.⁴ Most developmental disabilities are identified in childhood, and recent CDC findings identify a rate of 7% among children.⁵ However, this training will focus on the needs of adult patients with developmental disabilities, with an emphasis on intellectual disabilities and care at the end of life.

It's important to remember that the concept of disability is just as much social as it is medical. In many cases, for example, the impairments associated with a specific disability are just a function of the environment and the supports and barriers present within it.⁶ Additionally, everyone has varying degrees of impairment and skill; it is our cultural beliefs, however, that determine who we consider "disabled" and who we consider "non-disabled."

Why is it important to know about intellectual and developmental disabilities in end-of-life care?

Adults with intellectual disabilities face significant medical^{7,8} and psychiatric⁹ comorbidities. Adults with intellectual disabilities also have higher levels of health risk behaviors like poor nutrition¹⁰ and sedentary lifestyle.¹¹ Similar comorbidities and health risks have been found among those with other disabilities as well.¹² Thus, treatment of this population is often clinically complex.

People with developmental disabilities generally die younger than the general population, although there are significant variations people in this heterogenous population.¹³ There has been a dramatic increase in the life expectancy of those with intellectual disabilities over past decades,¹⁴ but life expectancy is still shorter than those without disabilities,

In some cases, the clinical advances that have increased life-expectancies have led to greater comorbidity and more difficult clinical presentations at the end-of-life. For example, among patients with Down syndrome, longer life expectancies have dramatically increased the risk of dementia at the end of life.¹⁵ Another example is the higher and earlier incidence of frailty among older adults with intellectual disability.¹⁶

Despite the need for more access and better care, however, people with intellectual and developmental disabilities often receive poorer care at the end of life. Specifically, among patients with intellectual and developmental disabilities, the following have been found:

- higher rates of premature mortality¹⁷
- low utilization of palliative care¹⁸
- provider assumptions of poor quality of life¹⁹
- inappropriate use of do-not-resuscitate orders¹⁹
- lack of disclosure of terminal illness by medical staff to the patient^{20,21} and
- insufficient communication of treatment plans and symptoms.²²

Additionally, among a sample from the United Kingdom, patients with intellectual disabilities were significantly more likely to have iatrogenic complications in care identified as contributing to their death.²³ Put simply, at the end of life, the voices of individuals with intellectual and developmental disabilities may not be heard, or disregarded. As a result, inappropriate or inadequate care may frequently be delivered.

These disparities have never been more salient than during the COVID-19 pandemic. One analysis found that those with developmental disabilities were 3 times more likely to die from COVID-19 than those without. Those with intellectual disabilities specifically were 2.75 times more likely.²⁴ In New York State specifically, during the first wave of the COVID-19 pandemic, individuals with IDD living in residential group homes died at almost eight times the rate of the general population.²⁵

As part of this project, we asked people with intellectual and developmental disabilities, as well as people who provide care to this population, to share their experiences. Here are some of the things they said:

Unfortunately, I feel people with disabilities do not receive the same treatment by health professionals as people without disabilities. I have experienced personally and in reviewing charts statements such as "Don't bother with a DNR" [and] "They have no quality of life because they can not speak." During the COVID pandemic individuals with disabilities were not even considered for potential lifesaving interventions. I feel this is due to the implicit bias of health professionals against people with disabilities.

Most medical providers that I meet for the first time will often make comments about how I am not really "that" disabled/ "how lucky I am" or they are surprised by my level of function. I've had doctors automatically rule out certain IADLS or ADLS that I would be able to perform based solely on my diagnosis before even evaluating me.

There [are] some times when it seems a provider regards me as lacking basic competence... I believe that there is a basic presumption that we are suffering and that our lives are not worth living and ought not be preserved sometimes.

Those with intellectual and developmental disabilities are a patient population who desperately need quality care. In the following modules, we will discuss how to tailor standard end-of-life care to meet this need.

Addressing our biases - Module #2

Discrimination of those with disabilities, both in medicine and in society at large, has a very long history. Many of us hold misconceptions and biases towards people with disabilities that are a legacy of that history. In turn, these biases can impact the care we deliver today. In this module, we will use research and cases reported in the media to discuss how to identify and challenge some of these biases.

We'll start with the story of Sarah. Sarah McSweeney was a 45 year old woman with quadriplegia and cerebral palsy. As explained in a National Public Radio story about her life,²⁶ Sarah communicated via sounds and gestures. She used a gastrostomy tube to eat and required others to push her wheelchair for mobility. She also loved country music, going to the mall, and getting her nails done.

Before being admitted to the hospital for aspiration pneumonia, Sarah and her guardians had filled out a POLST form indicating that Sarah was to be "full code." This document specified that Sarah wanted to receive mechanical ventilation and intubation if medically indicated.

However, when she was critically ill, Sarah's guardians reported significant pressure from her clinicians to change her code status to do-not-resuscitate. Here is one of them in her own words, describing a conversation with a physician.

"He said intubating her was a matter of risk versus quality of life," Conger recalls. "I was like, 'But she has quality of life.' And he looked at me and goes, 'Oh, she can walk? And talk?'" And I said 'Well, no, but there's a lot of people who don't walk who have full quality of life.' And he gets kind of irritated with me and left the room at that point."

Reducing suffering and improving quality of life is paramount in the practice of medicine at the end of life. But quality of life is a subjective concept that should be defined by the person living that life rather than anyone else. Research on this topic,^{19,27,28} as well as stories like Sarah's, shows that many clinicians may underestimate the quality of life of people with disabilities. These incorrect assumptions about quality of life may then impact what kind of care clinicians consider "futile" and lead to the delivery of inappropriate care.

Therefore, this is what we recommend:

-  **Many individuals with disabilities report high quality of life. Rather than assume, discuss with the patient, their family, and caregivers who know the patient well about what conditions they think would constitute a high and low quality of life for the patient.**

Sarah's story also shows that clinicians may hold incorrect assumptions about whether patients are competent to consent and provide input about the care they want at the end-of-life. This can lead to care that may violate patients' rights, and patients' wishes. The truth is that those with a wide range of intellectual disabilities, including severe intellectual disability, can and do play an active role in determining what kind of care they would like at the end of life and who they would like to make decisions on their behalf.

Many with disabilities, for example, are familiar with intensive medical procedures due to past treatment. Others may be acquainted with tracheostomy and gastrostomy tubes due to living in group home settings with residents who required them. Those with severe intellectual disability can express their preferences in a variety of ways, which can be used to identify goals of care.

As an example, consider Neil. As reported in a case study,²⁹ Neil was a man with severe intellectual disability. In the words of the authors, “[Neil] communicated using facial expression (he smiled a lot), sounds (his laughter was contagious), body language and behaviours some considered ‘challenging.’” A few years prior, Neil had tolerated a tracheostomy poorly, exhibiting his distress through his facial expressions and behaviors, which his family and caregivers documented through a diary and video. Now critically ill, Neil’s family were asked to decide whether he should undergo another tracheotomy, which could potentially prolong his life. Based on their documentation of Neil’s preferences, the family decided not to proceed with the tracheotomy. In the words of his father, Neil had clearly shown that “if he had a choice he wouldn’t want that bloody thing again.” Neil died a few days later.

Sarah and Neil’s cases show that patients with intellectual and developmental disabilities may have specific wishes about their end-of-life care. These wishes should be pragmatically sought out however possible, and be respected like those of any other patient.

- ✚ **Patients with intellectual and developmental disabilities can and do communicate preferences for end-of-life care, sometimes in ways you may not be familiar with. These preferences should be probed, documented, and respected.**

Some individuals may make decisions through a formal process that disability advocates refer to as “supported decision-making.” The goal of supported decision-making is to put the person with disabilities in charge of their care with respect and dignity to the extent practicable.³⁰

The supported decision-making process may occur over the course of months, depending on the complexity of the decision and the communication abilities of the individual. A facilitator works with the person to identify what the person with disabilities wants help with, who will help them, and how they will be helped. This process results in a Supported Decision-Making Agreement that details how the person with disabilities would like to make important decisions about topics like medical care. It can also result in creation of health care proxy documents that identify surrogate decision-makers.

Of course, this process is often not possible during an inpatient hospital stay. Thus, within the clinical constraints of end-of-life care, we recommend clinicians do the following:

- ✚ **Ask patients and family members if they have a Supported Decision-Making Agreement that outlines how care decisions should be made, and if so, follow it.**
- ✚ **Involve patients with intellectual disabilities in decision-making about end-of-life care whenever and however possible.**

Lastly, just like anyone else, people with intellectual and developmental disabilities have many identities, influenced by factors like race, gender, and culture. These identities and lived experiences may play a role in the kind of care a patient wants at the end of life and how the patient and their family talk about serious illness. Cultural competency and humility surrounding these issues is just as important in treating patients with disabilities as it would be for any other patient.

Navigating the system - Module #3

Those with intellectual and developmental disabilities have specific legal protections that can impact end-of-life care. In this module, we will give a quick overview of this medico-legal information. This information is current as of July 2021 and is specific to New York State. It does not constitute medical or legal advice and should not be used in place of Weill Cornell Medicine or New York Presbyterian policies. The authors and Center for Research on End-of-Life Care are not liable for any action or decision, or lack thereof, resulting from the use of this resource.

The need for legal protections for those with developmental disabilities at the end of life stems from a long history of medical mistreatment across the western world. In New York State, one shocking and still-recent example is the Willowbrook State School. Located on Staten Island, deeply inhumane conditions and highly unethical medical experimentation led to the closure of this massive state institution in the 1980's.³¹

In response to these abuses, state laws were passed affording unique legal protections to the thousands of people who once lived at Willowbrook. Specific to end of life, members of the "Willowbrook class" who do not have capacity to make medical decisions and do not have a healthcare proxy are served by a special advisory panel called the Consumer Advisory Board, or CAB. This panel acts as their advocate and surrogate decision-maker on matters related to end-of-life care. As of February 2020, approximately 2300 individuals who lived at Willowbrook were still alive, with many still in New York City and the surrounding areas.³² As these individuals age, end of life care for this population, and when indicated, proper coordination of care with the Willowbrook consumer advisory board, will be necessary.

Additionally, research we have conducted using medical records from hospitals in New York indicate that patients with intellectual disabilities may be more likely to receive CPR at the end of life and be less likely to have a DNR. Our findings speak to the difficulty of advance care planning for this vulnerable population, but also show that patients with intellectual disabilities may be more frequently receiving burdensome end-of-life care compared to other patients. As a result, we believe it is especially important to know how to navigate the complex legal context for patients with intellectual and developmental disabilities so that they can be provided with equitable and timely end-of-life care.

MOLST forms and treatment decisions

All individuals with intellectual or developmental disabilities may complete a MOLST form. MOLST stands for Medical Orders for Life Sustaining Treatment. This form serves to dictate what kind of care a seriously ill patient will receive or avoid at the present moment and near future.

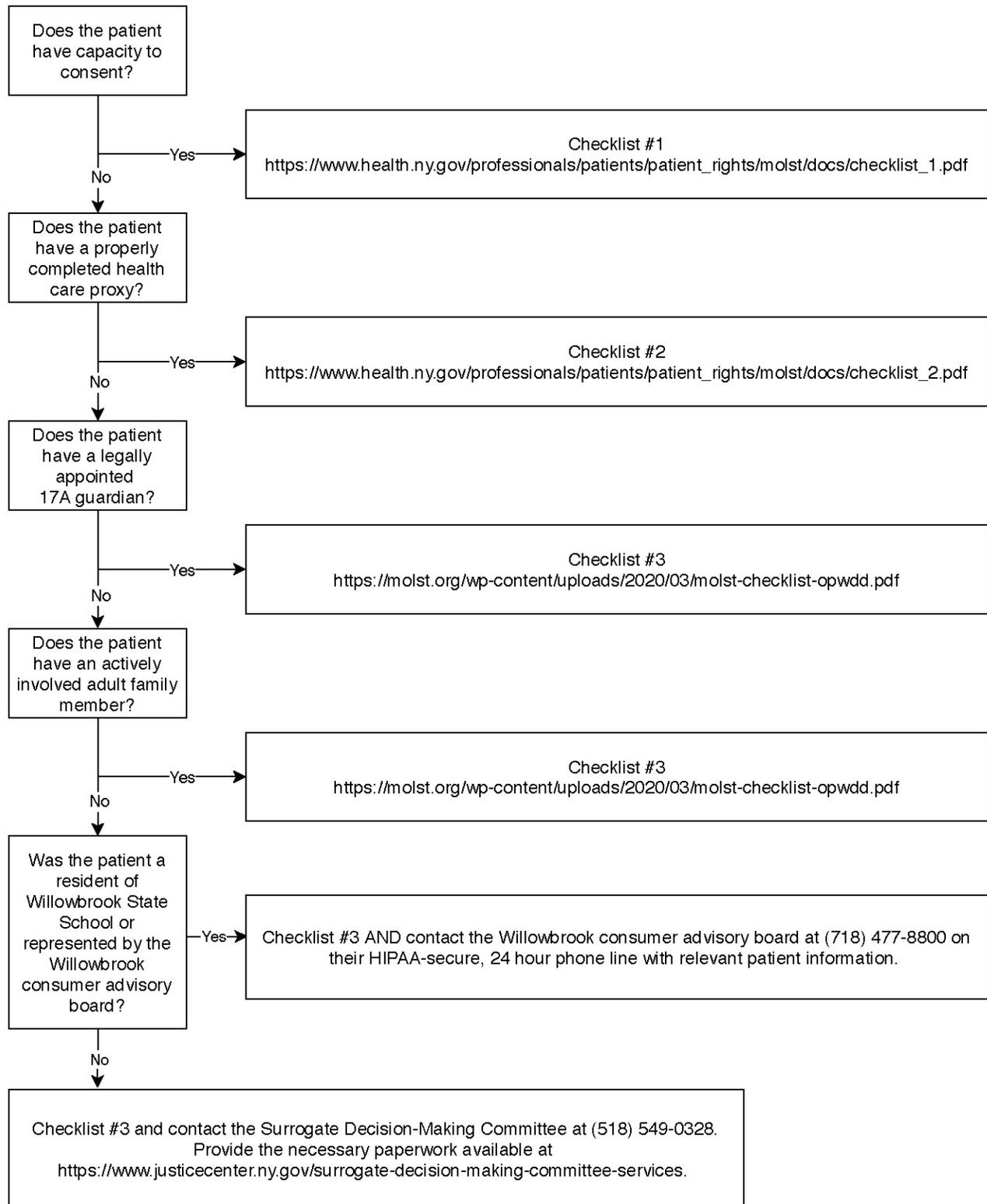
Procedures for completing a MOLST form are different for those with intellectual/developmental disabilities. Specifically, New York State law indicates four classes of patients with intellectual/developmental disability, each with different legal protections and steps to complete in the form of a checklist before the MOLST form can be enacted. The four classes are as follows:

- Those with capacity to make medical decisions
- Those without capacity to make medical decisions and have a health care proxy
- Those without capacity to make medical decisions and do not have a health care proxy
- Those without capacity to make medical decisions and do not have a health care proxy and are members of the Willowbrook class

The website shown here provides instructions for each class: <https://molst.org/covid-19-guidance/opwdd-individuals/>. We've also made a flowchart of these instructions, which you can download from this link. [*Flowchart on page 7*].

Decisions regarding capacity must be made in consultation with a physician certified by the Office of People with Developmental Disabilities. To find physicians at your New York Presbyterian hospital who have this certification, or for any other question about medical decision-making, call their 24-hour hotline at [\(855\) 696-7933](tel:8556967933).

Guide for completing a MOLST form for seriously ill patients with intellectual or developmental disabilities



This guide is based off of information provided at <https://molst.org/covid-19-guidance/opwdd-individuals/> current as of January 1st, 2021. This form is for information purposes only and is not legal or medical advice nor should it be used in place of any New York Presbyterian or Weill Cornell Medicine policies. The authors and Center for Research on End-of-Life Care are not liable for any action or decision, or lack thereof, resulting from the use of this resource.

Communicating with patients and families - Module #4

Many members of the disability community communicate in ways that you may not be familiar with. Examples include sign language or assistive communication tools like eye gaze technology. Some people with developmental disabilities speak slower or pronounce words differently. Other people with disabilities communicate verbally without issue.

Especially for individuals with intellectual disability, communication has been identified as a significant barrier to providing effective palliative care.²² Thus, improving communication may be one of the most effective things you can do to improve care for this population. In this module, we will present simple guidelines for communicating with patients with disabilities. These guidelines are based on the research of Irene Tuffrey-Wijne, an expert in end-of-life care for individuals with developmental disabilities. We thank her and her colleagues for their work.

First, we'll start with tips that apply broadly to patients with disabilities.

Learn how your patient communicates.

Because there are many different modes of communication, understanding what works best for your patient can bring clarity to conversations and reduce stress and anxiety for both parties. Do not assume that a patient cannot communicate or that communicating with them is unnecessary. If you are having trouble communicating or are unsure, companions at the bedside can give you baseline information about how the patient communicates.

As one of the stakeholders we interviewed said:

There are people who can't communicate or talk, so [doctors] need to be patient with them... slow it down and don't talk so fast.

When communicating with nonverbal patients, pay close attention to body language and facial expressions, as well as any sounds they may vocalize. Use close-ended questions so that patients can indicate yes or no.³³

Communicate with the patient, not their supporter.

Very often, individuals with disabilities report that medical staff will address their family members rather than speaking with them. Doing so cuts the patient out of the decision-making process and violates the ethical principle of patient autonomy. Whenever possible, speak directly to the patient.

Build trust.

Many of our stakeholders expressed that they believe the medical system treats people with disabilities unfairly. Some patients and families may distrust healthcare providers due to knowledge of systemic discrimination by the medical system.^{34,35} Others may have had personal experiences that have affected how they feel about the medical system and impact decisions they make about care. For example, one of our stakeholders discussed feeling pressure from physicians to place her son in a residential facility, and explained how it affected her, saying, "I don't want to be encouraged to make medical decisions for my son that are placing my quality of life over his quality of life." Some patients with intellectual disabilities may also be understandably anxious and upset if not properly oriented in a hospital setting, and thus unwilling to partake in physical exams or procedures.²²

All of this is to say that acknowledging and overcoming gaps in trust among patients and families is deeply necessary, especially at the end of life. Using active listening and empathy is key, just as it would be for any other patient. Providing clear information and rationales for procedures and medical decisions may also help patients and families gain a better sense of understanding and trust with the medical team. One of our stakeholders recommended the following:

Acknowledge that there is a conflict with viewing disability through the lens of the traditional medical model. And know that how you treat people with disabilities throughout their lifespan can adversely affect a family's relationship [with the medical system]. What you do matters. What you say matters.

Now, let's discuss communicating specifically with those who have intellectual disabilities.

🚩 **Be as clear as possible and check for understanding.**

Communicate clearly with patients, keeping medical terminology to an absolute minimum. Pause frequently to ask open-ended questions or use teach-backs to check understanding.

🚩 **Communicate in concrete, rather than abstract terms.**

Using euphemisms can greatly increase the risk of a misunderstanding. Abstract concepts, such as time, may also be difficult to understand. Therefore, Tuffrey-Wijne and McEnhill recommend framing communication in context that the patient is familiar with, such as using holidays or other "index events" as a way of taking history. As an example, they suggest asking "Did you have the pain at Christmas?" rather than "How long have you had the pain?"²² Even the concept of illness may be relatively abstract or meaningless to a patient. Instead, focus on what the illness means for them.

One helpful technique may be to use visual aides to help patients make decisions. Drawing pictures or searching for images on your cell phone can help show a patient exactly what you're talking about.

When appropriate, it may also be helpful to center communication in a context that the patient understands and appreciates. For example, one patient with developmental disabilities was having difficulty accepting the death of a close friend. This patient was very familiar with taking the subway, so his mother said the following: "Life is like a train ride. Everybody has their stop. When it's their stop, they have to get off. That's the way it is." This helped the patient accept his friend's death and understand it in his own way.

Communicating about prognosis

Lastly, clinicians, caregivers, and family members may be especially hesitant to disclose a terminal prognosis to a patient with intellectual disability.³⁶ However, we know that patients' perception of their illness³⁷ and discussions about end of life care³⁸ are closely linked to the kind of care patients receive. Therefore, deliberately concealing information about a terminal illness for a patient just because they have an intellectual disability disenfranchises them and prevents them from making informed decisions about their own care. Instead, palliative and critical care clinicians can play an essential role by assessing what a patient with intellectual disabilities may already understand about their terminal illness, what they want to learn, and providing that information when appropriate.

Disclosure of terminal prognosis to patients with intellectual disability is a process, not a one-time event. This process is unique to each patient, and any potential harms from disclosure should be weighed with the benefits. Disclosure should be made with the best interests of the patient in mind.

Irene Tuffrey-Wijne's framework for "breaking bad news" involves two main steps.³⁹ First, one can assess whether the patient with intellectual disabilities would benefit from disclosure of the terminal prognosis by speaking with the patient, their family and caregivers.

Here are some questions that can serve as a guide. Gathering information from the patient, their family, and their close caregivers will often be necessary in answering these questions.

- Is the patient able understand abstract concepts like death, illness, and time?
- Will they be able to retain this information?
- What does the patient already know about their illness?
- Does the patient want to know more about their illness?

Then, news can be broken into simple chunks, starting with the most important information first. Focus on how the bad news fits in to the immediate context of the patient's life. For example, how does this bad news affect them today? What will change as a result of this bad news? What won't change as a result of this bad news? As discussed in the previous section, communicating clearly and checking for understanding is key.

Excellent resources exist to help clinicians and family members decide whether disclosure of a terminal prognosis is appropriate for a patient with intellectual disabilities and engage in the process. Clinicians and family members can visit <http://www.breakingbadnews.org/> for guidelines on this topic. Illustrated books for adults with intellectual disabilities on terminal illness, death, and grief are also available at <https://booksbeyondwords.co.uk/bookshop/paperbacks/am-i-going-die>.

Assessing pain - Module #5

Treating pain is an essential part of palliative care and end-of-life care. Pain, however, is an inherently subjective experience, and often requires patient communication to facilitate assessment and treatment. Therefore, pain may be especially difficult to identify for patients who communicate in ways that their clinician may not be familiar with.

Given this context, it is unsurprising that research has shown that patients with intellectual and developmental disabilities receive poorer pain management.⁴⁰ Compounding this problem, those with intellectual⁴¹ and developmental⁴² disabilities may experience pain more frequently than those without. Although no research has yet examined disparities in pain treatment specific to the end of life, it is conceivable that this trend remains.

Myths about pain and people with disabilities have existed for decades. Because these myths may contribute to disparities in pain management, we're going to dispel them.

The first myth is that individuals with intellectual or developmental disabilities have higher pain tolerances or are "immune" to pain.⁴³ Instead, the truth is this: patients with intellectual disabilities, especially older adults, experience significant pain that is often undertreated.⁴⁴

Another myth is that self-injurious or "non-compliant" behaviors are responsible for pain in patients with intellectual and developmental disabilities. The truth is that self-injurious behaviors can often be attempts at coping with undetected root causes of pain, and should spur further assessment.⁴⁴

To assess pain in patients with limited verbal communication, experts in the field^{45,46} recommend doing the following:

- ✚ **Always start by asking the patient, as self-report is the best measure of pain.**
- ✚ **Consult with family members and caregivers familiar with the patient to identify potential changes from baseline and understand how the patient expresses pain.**
- ✚ **For systematic monitoring of pain over time for nonverbal patients, use the Non-Communicating Adult Pain Checklist. This tool is easy to fill out and can be found here: <https://pubmed.ncbi.nlm.nih.gov/19900787/>**

Like in any other palliative care context, the essential goal is to identify the source of the pain for the patient. However, for those with limited communication, this may be especially difficult. Oberlander, Burkitt and Symon note that certain symptoms associated with developmental disabilities may be helpful in a differential diagnosis for an "irritability of an unknown origin." These include GERD, dental infection, constipation, injury, or skin infections associated with lack of mobility.

We'll use the story of Elliot as an example. Elliot was an adult with severe intellectual disabilities who lived in a group home setting. One day, he began refusing to eat or participate in activities and cried when food was placed in front of him. Because he could not verbally express why he was not eating, staff provided Elliot with some of his favorite foods, like ice cream and tea, to see if he would be willing to eat them. He refused these foods as well. This gave staff confidence that his behavior wasn't simply "acting out," but was potentially indicative of GI problems instead. Further workup identified acid reflux as a source of pain for Elliot, which was then able to be managed effectively with proton pump inhibitors.

This example shows that presentations of pain may manifest in unique ways for patients with intellectual and developmental disabilities. Identifying the source of pain may require clinicians to be pragmatic and rely upon people who know the patient well to help.

In closing, we believe that those with disabilities deserve end of life care that minimizes suffering and maximizes autonomy and respect. We hope that the information provided in this presentation gives you the skills to make that a reality in what are often incredibly difficult circumstances.

This marks the end of our videos. A one page summary of what we've discussed is available for download [*Handout on page 11*]. We hope that you have found this presentation useful and welcome your feedback. Thank you very much for your time.

We would also like to thank our stakeholders for their input on these videos, as well as the researchers whose work this training is based on. Additionally, we would like to thank the visual artists whose work was used in these videos- Maurice Barnes, Charmaine Jones, Robert Corcoran, and Nonja Tiller- as well as ArtEnables. Lastly, we would like to thank the patients and families whose stories we have incorporated into these videos, and the WITH Foundation, which sponsored this work.

Clinical pearls for caring for people with intellectual/developmental disabilities at end-of-life

Making decisions about care

- ✚ Many individuals with disabilities have high quality of life. Rather than assume, discuss with the patient, their family, and caregivers who know the patient well about what conditions they think would constitute a high and low quality of life for the patient.
- ✚ Patients with intellectual and developmental disabilities can and do communicate preferences for end-of-life care, sometimes in ways you may not be familiar with. These preferences should be probed, documented, and respected.
- ✚ Ask patients and family members if they have a Supported Decision-Making Agreement that outlines how care decisions should be made, and if so, follow it.
- ✚ Involve patients with intellectual disabilities in decision-making about end-of-life care whenever and however possible.

Assessing pain

- ✚ Always start by asking the patient, as self-report is the best measure of pain.
- ✚ Consult with family members and caregivers familiar with the patient to identify potential changes from baseline and understand how the patient expresses pain.
- ✚ For systematic monitoring of pain over time for nonverbal patients, use the Non-Communicating Adult Pain Checklist. This tool is easy to fill out and can be found here: <https://pubmed.ncbi.nlm.nih.gov/19900787/>

Communicating with any patient with disabilities

- ✚ Learn how your patient communicates.
- ✚ Communicate with the patient, not their supporter.
- ✚ Work to build trust.

Communicating with patients with intellectual disabilities

- ✚ Be as clear as possible and check for understanding.
- ✚ Communicate in concrete, rather than abstract terms.
- ✚ Thoughtful and appropriate disclosure of terminal prognosis may be warranted, depending on patient desire and capacity.

Works Cited

1. Centers for Disease Control and Prevention. Developmental Disabilities. 2020; <https://www.cdc.gov/ncbddd/developmentaldisabilities/index.html>, 2020.
2. American Association on Intellectual and Developmental Disabilities. Definition of Intellectual Disability. 2020; <https://www.aaidd.org/intellectual-disability/definition>.
3. McDermott S, Royer J, Cope T, et al. Using Medicaid data to characterize persons with intellectual and developmental disabilities in five US states. *American Journal on Intellectual and Developmental Disabilities*. 2018;123(4):371-381.
4. Maulik PK, Mascarenhas MN, Mathers CD, Dua T, Saxena S. Prevalence of intellectual disability: a meta-analysis of population-based studies. *Research in developmental disabilities*. 2011;32(2):419-436.
5. Zablotsky B, Black LI, Blumberg SJ. Estimated prevalence of children with diagnosed developmental disabilities in the United States, 2014-2016. 2017.
6. Oliver M. The social model of disability: Thirty years on. *Disability & society*. 2013;28(7):1024-1026.
7. Matson JL, Cervantes PE. Comorbidity among persons with intellectual disabilities. *Research in Autism Spectrum Disorders*. 2013;7(11):1318-1322.
8. Tyler J, Carl V, Schramm S, Karafa M, Tang AS, Jain A. Electronic health record analysis of the primary care of adults with intellectual and other developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*. 2010;7(3):204-210.
9. McCarron M, Swinburne J, Burke E, McGlinchey E, Carroll R, McCallion P. Patterns of multimorbidity in an older population of persons with an intellectual disability: results from the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA). *Research in developmental disabilities*. 2013;34(1):521-527.
10. Draheim CC, Stanish HI, Williams DP, McCubbin JA. Dietary intake of adults with mental retardation who reside in community settings. *American journal of mental retardation : AJMR*. 2007;112(5):392-400.
11. Temple VA, Walkley JW. Physical activity of adults with intellectual disability. *Journal of Intellectual and Developmental Disability*. 2003;28(4):342-353.
12. Reichard A, Stolzle H, Fox MH. Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States. *Disability and health journal*. 2011;4(2):59-67.
13. Landes S, Stevens J, Turk M. Heterogeneity in age at death for adults with developmental disability. *Journal of Intellectual Disability Research*. 2019;63(12):1482-1487.
14. Patja K, Iivanainen M, Vesala H, Oksanen H, Ruoppila I. Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of intellectual disability research*. 2000;44(5):591-599.
15. Hithersay R, Startin CM, Hamburg S, et al. Association of dementia with mortality among adults with Down syndrome older than 35 years. *JAMA neurology*. 2019;76(2):152-160.
16. Evenhuis HM, Hermans H, Hilgenkamp TI, Bastiaanse LP, Echteld MA. Frailty and disability in older adults with intellectual disabilities: results from the healthy ageing and intellectual disability study. *Journal of the American Geriatrics Society*. 2012;60(5):934-938.
17. Hosking FJ, Carey IM, Shah SM, et al. Mortality among adults with intellectual disability in England: comparisons with the general population. *American Journal of Public Health*. 2016;106(8):1483-1490.
18. Stein GL. Providing palliative care to people with intellectual disabilities: services, staff knowledge, and challenges. *Journal of palliative medicine*. 2008;11(9):1241-1248.
19. Tuffrey-Wijne I, Goulding L, Gordon V, et al. The challenges in monitoring and preventing patient safety incidents for people with intellectual disabilities in NHS acute hospitals: evidence from a mixed-methods study. *BMC Health Services Research*. 2014;14(1):432.
20. Bernal J, Tuffrey-Wijne I. Telling the truth—or not: disclosure and information for people with intellectual disabilities who have cancer. *International Journal on Disability and Human Development*. 2008;7(4):365-370.
21. Ryan K, Guerin S, Dodd P, McEvoy J. Communication contexts about illness, death and dying for people with intellectual disabilities and life-limiting illness. *Palliative & supportive care*. 2011;9(2):201.
22. Tuffrey-Wijne I, McEnhill L. Communication difficulties and intellectual disability in end-of-life care. *International journal of palliative nursing*. 2008;14(4):189-194.

23. Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet*. 2014;383(9920):889-895.
24. Fair Health, West Health Institute, Makary M. *Risk Factors for COVID-19 Mortality among Privately Insured Patients: A claims data analysis*. 2020.
25. Landes SD, Turk MA, Formica MK, McDonald KE, Stevens JD. COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disability and Health Journal*. 2020;13(4):100969.
26. Shapiro J. As Hospitals Fear Being Overwhelmed By COVID-19, Do The Disabled Get The Same Access? 2020; <https://www.npr.org/2020/12/14/945056176/as-hospitals-fear-being-overwhelmed-by-covid-19-do-the-disabled-get-the-same-acc>.
27. Ubel PA, Loewenstein G, Schwarz N, Smith D. Misimagining the unimaginable: the disability paradox and health care decision making. *Health Psychology*. 2005;24(4S):S57.
28. Iezzoni LI, Rao SR, Ressler J, et al. Physicians' Perceptions Of People With Disability And Their Health Care: Study reports the results of a survey of physicians' perceptions of people with disability. *Health Affairs*. 2021;40(2):297-306.
29. Watson J, Wilson E, Hagiliassis N. Supporting end of life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability. *Journal of applied research in intellectual disabilities*. 2017;30(6):1022-1034.
30. Supported Decision-Making New York. Making Decisions. 2019; <https://sdmny.hunter.cuny.edu/for-dms/making-decisions/>.
31. Flynn S. *A History and Sociology of the Willowbrook State School*. Taylor & Francis; 2017.
32. Weiser B. Broken Promise of Better Life After Being Abused at Willowbrook. *The New York Times*. February 21st, 2020; A1.
33. Musachio R. Let Nonverbal Patients Communicate. 2011; <https://www.levelaccess.com/let-nonverbal-patients-communicate-2/>, 2021.
34. Johnson E. Disability, Medicine, and Ethics. *AMA Journal of Ethics*. 2016;18(4):355-358.
35. Mosley T, Raphelson S. 'Who Are The Most Likely To Be Saved?': Alice Wong On Living With Disability During COVID-19. April 8th, 2020; <https://www.wbur.org/hereandnow/2020/04/08/coronavirus-disabilities-ventilator>.
36. Tuffrey-Wijne I, Bernal J, Hollins S. Disclosure and understanding of cancer diagnosis and prognosis for people with intellectual disabilities: findings from an ethnographic study. *European Journal of Oncology Nursing*. 2010;14(3):224-230.
37. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *Jama*. 1998;279(21):1709-1714.
38. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Jama*. 2008;300(14):1665-1673.
39. Tuffrey-Wijne I, Watchman K. Breaking bad news to people with learning disabilities and dementia. *Learning Disability Practice*. 2015;18(7):16-23.
40. McGuire B, Daly P, Smyth F. Chronic pain in people with an intellectual disability: under-recognised and under-treated? *Journal of Intellectual Disability Research*. 2010;54(3):240-245.
41. Walsh M, Morrison TG, McGuire BE. Chronic pain in adults with an intellectual disability: prevalence, impact, and health service use based on caregiver report. *Pain*. 2011;152(9):1951-1957.
42. VAN DER SLOT WM, Nieuwenhuijsen C, VAN DEN BERG-EMONS RJ, et al. Chronic pain, fatigue, and depressive symptoms in adults with spastic bilateral cerebral palsy. *Developmental Medicine & Child Neurology*. 2012;54(9):836-842.
43. LaChapelle DL, Hadjistavropoulos T, Craig KD. Pain measurement in persons with intellectual disabilities. *The Clinical journal of pain*. 1999;15(1):13-23.
44. de Knecht NC. Pain in older adults with intellectual disabilities. In: *Pain Management in Older Adults*. Springer; 2018:73-82.
45. Oberlander TF, Burkitt C, Symon F. Pain in individuals with intellectual disabilities. *Clinical pain management: a practical guide Blackwell Publishing Ltd, Oxford*. 2011:326-334.
46. Doody O, E. Bailey M. Pain and pain assessment in people with intellectual disability: Issues and challenges in practice. *British Journal of Learning Disabilities*. 2017;45(3):157-165.