What professional ethics consultants need to know about I/DD

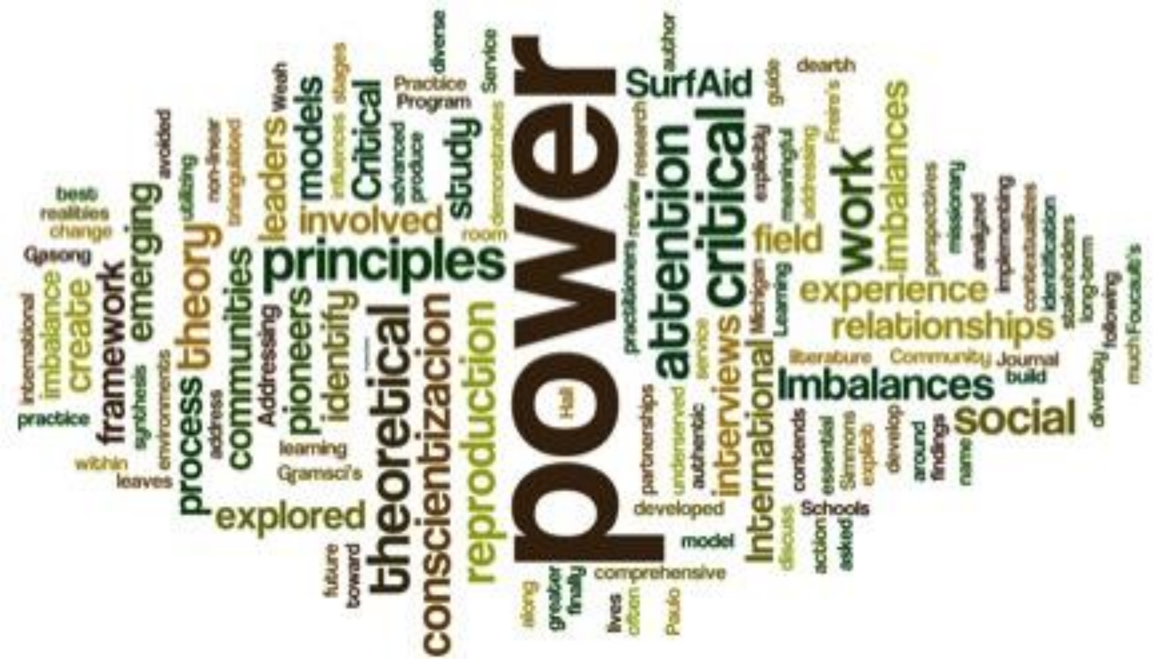
Teresa A. Savage, PhD, RN
University of Illinois at Chicago
College of Nursing

- The presenter has no conflicts of interest to disclose

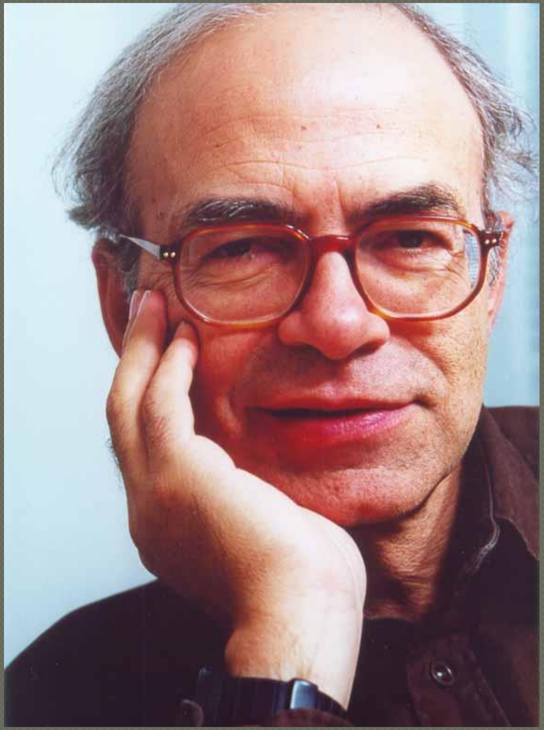
Objectives: At the end of this session the learner will be able to:

- Have resources to address the myths and misperceptions about the lives of people with I/DD
- Facilitate the recognition bias
- Assist ethicists to view cases through a social model of disability

Tension between ethicists and disability activists



Tension between bioethicists and people with disabilities



Bioethics: Introduction to theories from hell (Alice Mailhot, 1994)

- "If I were listing the most dangerous people in the U.S. today, bioethicists, aka medical ethicists, would top my list—'way above skinheads, whose beliefs they appear to share."
- "Bioethicists live off tax dollars and wealthy foundations. They teach medical professionals and community elites to decide who lives and who dies."
- "Bioethicists see cost savings in cheap and early death…."

Some of the sources of tensions:

- HCP’s lack of knowledge about life with disability (“Ableism”); have not embraced the need to know
- Abundant literature on negative perceptions of QOL, which can affect willingness to offer treatments, and framing of information/ choices.
- HCP’s contact bias; they interact with patients often when pts are most vulnerable
- Health care settings often not accessible and user friendly for pwd’s (overt and subtle messages of devaluation)
- Disability seen as “failure” of health care system
- History- e.g., sterilization, research, frontal lobotomies, focus on “normalization” (i.e., post-polio), bias toward institutionalization

- Are these tensions based on lack of knowledge?
- Or a belief that life with disability can only be intolerable?
- Or a view that people with disabilities are a burden for families and for society?

"There must be some mistake.
I was on the Ethics Committee for 22 years."

- How do you educate the ethics consultants about life with disability?
- Personal conversations
- Presentations at conferences
- Publications in ethics journals
- Feedback on individual situations
- Presentation to ethics consultants or ethics committee members
  - Suggested Content:
    - First person narratives
    - Value clarification exercise
    - Case presentation
    - Suggested readings/videos/websites

First activity

- Common myths and misperceptions about people with disabilities
- Excerpts from "Healthcare Stories" from the DREDF website
- www.dredf.org/healthcare-stories
- Excerpts from NIH-funded study on end-of-life issues

Myths and Misperceptions

- **Children with developmental disabilities are a burden to their families.**
- **People with developmental disabilities cannot learn.**
- **It is not offensive to use the R-word.**
- **Individuals with developmental disabilities should not be part of the community.**
- **Adults with developmental disabilities cannot live independently.**
- **Those with developmental disabilities do not have the same feelings as other people.**
- **There is nothing one person can do to help eliminate the barriers confronting people with disabilities.**

Charlie's story

- http://dredf.org/healthcare-stories/2013/02/19/luise-custer-and-charlie-tygiel/
- Born early, absence of corpus callosum, intractable seizures, had extensive brain surgery, then a vagal nerve stimulator which needed a battery replacement. Surgery went badly, lack of communication on the part of the surgeon to ask the mother how best to manage Charlie. Because of this episode, and one other, the mother believes, Charlie has a less functional life by far because of failed medical interventions or drugs that he was given that caused an adverse effect.

Charlie’s story: His mother’s plea

- “Of all the issues in the medical arena that concern me, it is perhaps the failure to correctly diagnose what's going on and have specialists who can address this thoughtfully and accurately. We also just need much more cultural literacy that everyone who works with our community somehow learns from the heart, as well as from the mind, how to understand the simple needs that go unattended. The anesthesiologist wishes he hadn't done what he did but he panicked because he was afraid of Charlie, he was afraid of the situation, he was afraid of my concern and those fears stand in the way of creating this cultural connection and understanding that then will bring a better diagnosis, bring quicker management of serious problems. “

Truth: People with I/DD are treated differently, often disrespectfully

- "…when I was in the emergency room with him it was because he was mentally retarded. And they wanted him out of there because he was yelling, and he was in pain. And I said you can give him something for pain. And they're like oh, he'll be fine. I'm like, if this was you or I, we would be having pain meds right now. I mean, this is not a guy who yells and screams…I had to walk out and call my mother-in-law and say you need to get here now. Because I felt like he was being almost like he was being abused." (#36)
- "…we were trying to decide on the necessity of a G tube and a J tube for feeding versus another option…[and the doctor said} 'Let him eat, enjoy his food and let him die.' That cold…And I nearly came unglued in that room. And I have a picture of my son. I said this is the person you're talking about. Not the person laying in that bed. And my son has a name. And he deserves treatment that you would give anyone else. He did end up with a G tube and a J tube and he lived a long time after. But I think you're right in that they treat handicapped people differently. "(#40)

- 35: I really don't feel the staff at any hospital probably are completely comfortable with our people…they're not accustomed…When our patients come in and somebody's yelling or doing whatever they might be doing, there's a whole uncomfortable scene.
- 36: It’s like they have no exposure to it so they just fear the unknown or something.
- 35: They should have some sort of preparation in their training.
- 36: More than just a class.
- 35: Some kind of training. Because after all, they do have a population in there. Our population are sent frequently. And then everybody says, now what are we going to do now? What are you going to do with him he's yelling, or he's doing something or other. And that's what people do. And they just don't seem to want to deal with it or they're not able to deal-- they need to extend their horizons a little bit, I think. Really.

Dispelling Myths…..

- Myth: The impairment is the problem.

  Excerpt: David Rivlin became paraplegic in his 20’s and lived in the community afterwards; after spinal surgery, he was rendered quadriplegic and ventilator-dependent. He was unable to find resources to allow him to live outside a health care facility, so he requested to be taken off the ventilator. A journalist from Detroit interviewed him and asked him why living in a facility was “two years of hell”.

Facilitated discussion

- Comments on myths and misperceptions and truths?
- What can you do at your own institutions to correct any myths and misperceptions?
- Who are your resources for information about disabilities and the lives of people with disabilities?

Second activity

- Identifying biases
- Exercise to clarify values and intolerable states

Exercise to clarify values and intolerable states

Kristi L. Kirschner MD (used with permission)

Pretend you are sitting down to write out an instructional advance directive (i.e., a document that would provide guidance to others about your wishes if you were in a state of incapacity and unable to tell them). Reflect on what you most value about your life. Please list the elements, qualities or conditions which you believe are critical or necessary for you to have a "good life."

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________

Now reflect for a few minutes about the conditions or states that would make you question whether your life was "worth living." Please list these conditions or states.

1.____
2.____
3.____
4.____
5.____

Finally, how certain are you about whether you would not want to live if you had the conditions or states listed above (assume with a reasonable degree of certainty that the condition or state is permanent)?

Not at all certain	moderately certain	very certain
1	2	3

1._________________
2._________________
3._________________
4._________________
5._________________

Exercise to clarify values and intolerable states

- Facilitated discussion
- Reflect on a consultation you completed when a patient had one of these conditions
- What, if anything, would you do differently?

Excerpt from End-of-Life study

- If -- if I'm real sick and ready to pass along to, I want -- I want them to let me just to go -- to go to -- let me down by myself and just try and let me stop -- if I can't breathe, please don't put me on oxygen, because I ready -- I ready to go to heaven.

- Woman: No, I don't want to go to -- I scared to say it…to a nursing home.

- Interviewer: What about if you were really really sick, if you were at the end of life, if you're dying, say?

- Adults with I/DD: Pull the plug…That's all. Umm, that's how I feel, I always said, I don't wanna be sick no more. I just want to die and go to heaven

- Interviewer: If you were dying, you wouldn't want anyone to know what's going on with you?
- Woman: Right.
- Interviewer: Okay. And why is that?
- Woman: Well, because it's probably sad for other people to hear about that kind of stuff.

Case discussion

19. 5. 2001

Case study: “Dexter”

He was born prematurely at 28 weeks and sustained bilateral intraventricular hemorrhages

- He also has lung damage and is oxygen-dependent
- He was in the NICU for several months, then was discharged home on oxygen, a feeding tube, and numerous medications
- Within a few weeks after going home, he was re-admitted to the hospital and child protective services removed him from the custody of his mother because of neglect
- Because of his extensive needs, he was admitted to a pediatric residential facility

At age 5

- Dexter continues to be oxygen-dependent
- He has spastic tetraplegic cerebral palsy
- He has a seizure disorder and has a ventriculo-peritoneal shunt
- He is non-verbal except for gutteral utterances
- He has an intellectual disability with skills measured below the 6 month level
- Over time he could eat orally
- His caregivers said they can tell who he likes or dislikes

Behavioral change

- His caregivers noticed a “fussiness” around feedings
- The medical director thought she palpated an abdominal mass; the surgeon ordered an immediate exploratory laparotomy for suspected intussuception
- His state guardian gave consent

Surgery and after

- The surgeon found that he had a number of tumors throughout his abdomen and she conditionally diagnosed him with Burkitt’s lymphoma, a virulent malignancy.
- She ordered an oncology consult.
- Pathology confirmed the diagnosis

Oncology consult and patient care conference

- A patient care conference was held, attended by the attending pediatrician, peds unit nursing staff, residential facility nursing staff, the oncologist, Dexter's state guardian, and the ethics consultant.
- Dexter's mother had never visited or called the facility where he lived; his grandmother visited once and was invited to the patient care conference, but did not attend despite transportation being arranged.
- The oncologist explained that Burkitt's lymphoma was a very aggressive cancer. He recommended radiation and chemotherapy. He estimated an 85% likelihood of cure. He also said he would recommend the exact same therapy for palliation.

Pros and cons of treatment raised at patient care conference

- **PROS**
- 85% likelihood of cure
- Intellectual disability may protect him from anticipatory nausea, anxiety, fear of dying
- Palliative care and curative treatment are identical

- **CONS**
- He must stay in hospital since he can't return to facility with IV's (TPN, IV analgesics)
- He will not understand what is happening to him; why he will be so sick from chemo
- The best outcome will return him to an already disabled condition
- "How will we know what he is experiencing since he can't tell us?"
- "This is God's way of correcting His mistakes."
- "What a waste [of resources]"

4-Box model of ethical decision-making

Medical indications

- Virulent malignancy
- GI involvement
- 85% chance of cure
- Palliative treatment identical to curative treatment

Patient preferences

- Unknown
- Parental preferences unknown
- Guardian consent based on medical recommendations
- Facility staff preferences

Quality of life

- Need to manage potential intense pain
- Will continue to need oxygen, tube feedings, anticonvulsants, etc
- Functional level likely to remain the same
- May not be able to return to facility

Contextual features

- Best outcome will be to return to baseline with same life span potential
- No biological family involvement
- Public aid to cover all costs

What should be done?

- Curative treatment
- No curative treatment; refer to hospice

Facilitated discussion

- What kind of power does the ethics consultant have in this case?
- What should be the prevailing values in decided what should happen to Dexter?
- If Dexter did not have his disabilities, would there be any question about treating him?
- Is it relevant that he is a ward of the state?
- One person called his treatment "a waste of resources"—is this a waste of resources?
- What is the threshold for a child with multiple disabilities to merit treatment?
- If palliative and curative treatment are identical, how can non-treatment be justified?
- Other issues?

Outcome

- Dexter initially responded to treatment but relapsed despite treatment.
- Tumors grew on his jaw and behind one eye, causing it to protrude.
- Palliative treatment was begun with aggressive pain management via morphine drip.
- The dosages required to reduce his signs of pain were much higher than what peds nurses were accustomed to giving, so the pediatric oncology CNS worked with them.
- The staff nurses from the facility kept a 24-hour vigil with him until he died.

Start the dialogue!

- Consider modifying the content to suit the audience (professional, lay, both?)
- What is the main message you want them to have at the end of the session?
- Social model of disability
  - Disability is not a state of the body, but a lack of fit between the body and the social/physical/ attitudinal environment that leads to social limitations or disadvantage

https://www.youtube.com/watch?v=VAM9nh8WC-8