

Three reasons to stop saying, “Not compatible with life”

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By the end of this session, you will:

Recall	Share	Recognize
Three reasons to stop saying, "Incompatible with Life"	Stories of survivors for conditions historically labeled "Incompatible with Life"	Opportunities to educate other medical professionals

“No matter what people tell you, words and ideas can change the world”

- Robin Williams

Related
terms to stop
using

→ Variable
meanings &
concealed
value
judgements



Futile = no way for it to achieve
its physiologic aim



Lethal = Latin 'letalis' (deadly)



Quality of life

#1. “Not Compatible with Life” is rarely true

“There is no effective treatment that will prevent a condition, disease, or injury from causing death in the near future”

Chervenak, McCullough. J Med Ethics 2012

Condition + life prolonging treatment = 100% Death

#1. “Not Compatible with Life” is rarely true

Not Compatible with Life

Condition + life prolonging treatment

= 100% Death

Examples:

Genetic error in making ATP
(Mitochondrial disorders)

Compatible with Life

Condition + life prolonging treatment

= Some Death + Some Life

Examples:

Cancer
Heart attack
Stroke
Large VSD
Prematurity

Conditions	Longest Reported Survival
Anencephaly	2.5 years
Trisomy 18	50 years
Trisomy 13	27 years
Thanatophoric Dysplasia	11 years
Renal Agenesis	7 years

*Data for live births (i.e. not terminated during pregnancy), mostly comfort-focused care



Megan lives with parents, Ron and Sara Hayes, in Oklahoma City

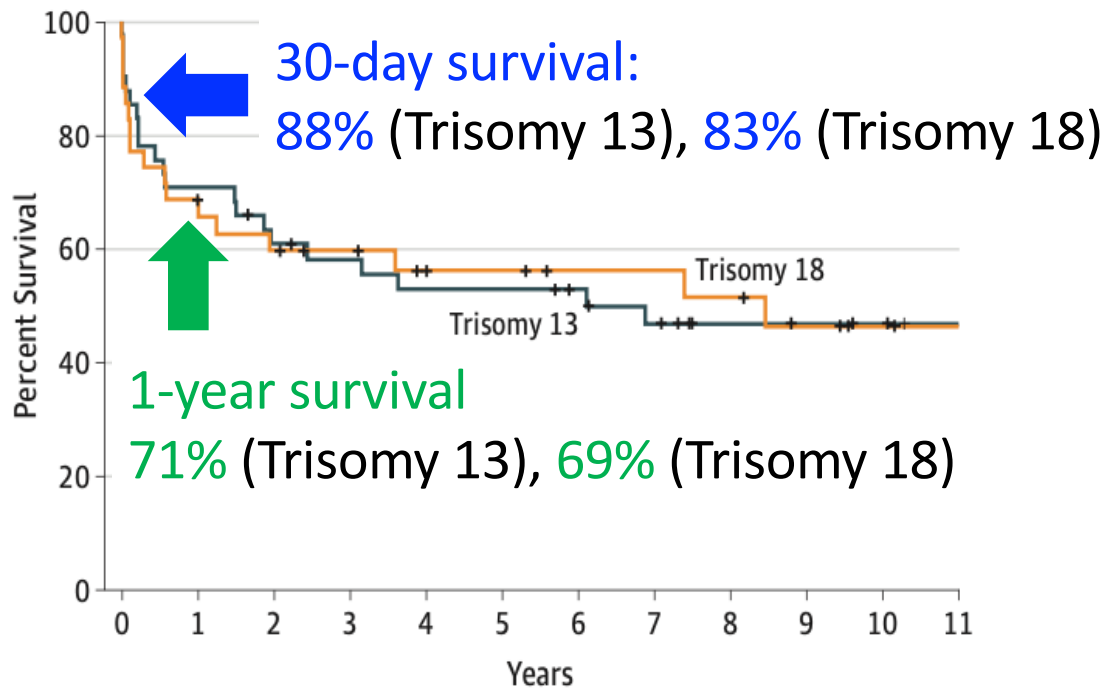
Megan Hayes (full Trisomy 18) Turns 40 years Old!

By [Terre Krotzer](#) | July 5, 2020 <https://trisomy.org/blog/megan-hayes-turns-40-years-old/>

Trisomy 13 & 18: High Survival After 1st Surgery



N= 76 (1991-2012)



Trisomy 18



THEN

Trisomy 13



NOW



'Trisomy 18.' Eliza Murphy. Lovewhatmatters.com



@chrisulmer (SBSK)

Thanatophoric Dysplasia

Thanatophoric: Greek for “death bearing”

Some Patients: Respiratory Support → Survive
Charlie: sprints off vent age 5, decannulated age 10

Foramen magnum very narrowed → Apnea;
Surgery (FM decompression) well tolerated

Carroll et al. Palliative Medicine Reports 2020



FIG. 1. Charlie at nine years of age in the front yard of his home.



Thanatophoric Dysplasia

Developmental delay (~2 to 5-year-old)

Charlie @ 11 years

Speaks full sentences on iPad

Feeds himself, Uses motorized wheelchair

Not associated with pain during life

Treatment:

Vosoritide stimulates bone growth

Anencephaly: Baby K (1992 to 1995)

Born via C/S at Fairfax Hospital in Virginia

Mechanical ventilation started at birth

Mother refused comfort-focused care because of faith

Tracheostomy placed

Weaned off ventilator after 6 weeks

Renal Agenesis

Abigail Rose born at 28 weeks

- 2012 Portland, OR
- In utero weekly amnioinfusions x 5 weeks
- No pulmonary hypoplasia at birth
- Peritoneal dialysis x 9 months: Stanford NICU
- Renal transplant at 2.5 years from Father

Renal Anhydramnios Fetal Therapy (RAFT) trial
at Mayo Clinic and Johns Hopkins



@HerreraBeutler March 2019

#2. “Not Compatible with Life” Reflects our Biases

Often, “Not Compatible with Life” means:

“The condition is not worth treating”

“The life is not worth saving”

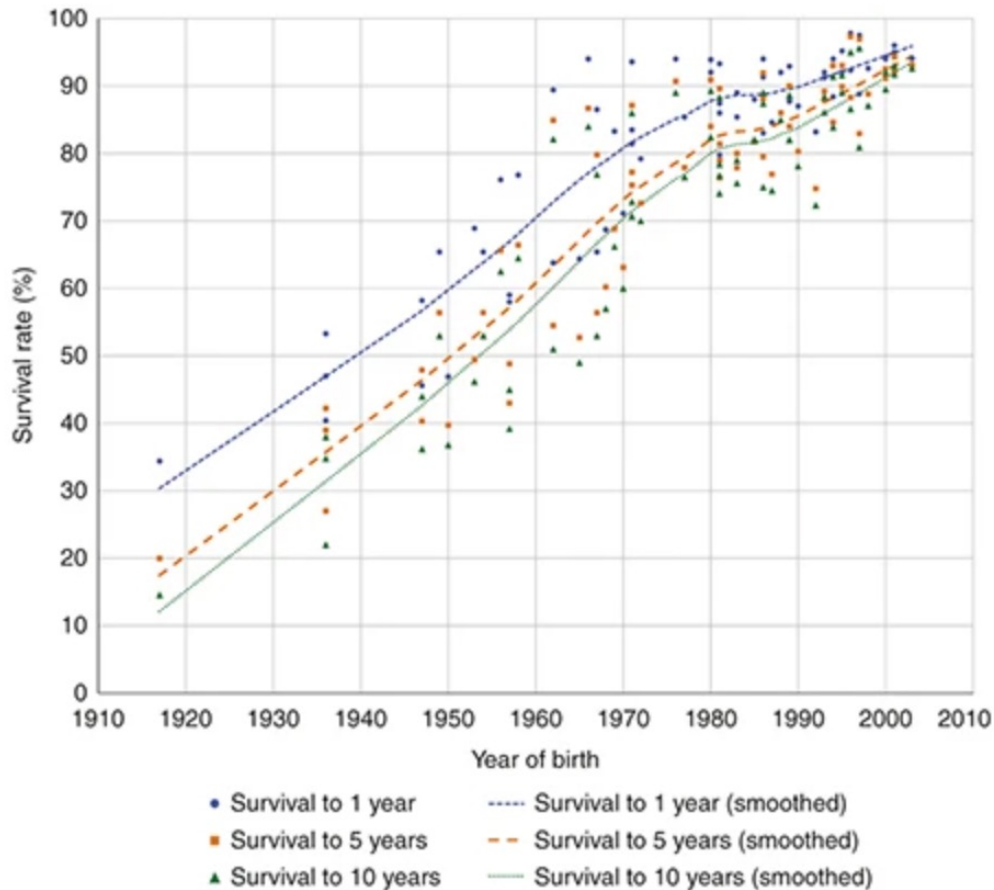
→ Judgment about value of life with severely impaired cognition

→ Places higher value on intelligence and physical ability

Reflects a time of strong paternalism in medicine

Opinion disguised as data

Life Expectancy for Persons with Trisomy 21



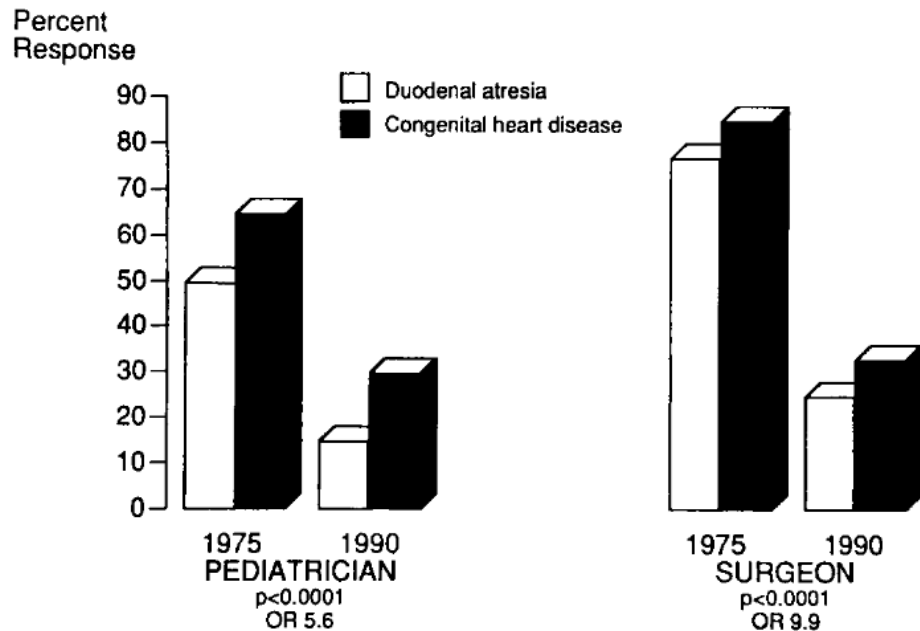
In 1960,
Rapid rise in survival began
70% survived to 1 year
Life expectancy ~ 12 years

By 1980s,
93% survived to 1 year
Life expectancy ~ 25 years

By 2010 Life expectancy ~ 58 years

Graaf et al. American College of Medical Genetics and Genomics. 2016

% Agreement to Withhold Life Saving Surgery for Persons with Down Syndrome



Haslam et al. Journal of Child Neurology 1992

Historically, persons with Trisomy 21 were institutionalized & excluded from public school

1971 Wyatt vs. Stickney: People in institutions have rights to treatment and education

1975 Individuals With Disabilities Education Act

1980 Civil Rights of Institutionalized Persons Act

Down Syndrome Human and Civil Rights Timeline
globaldownsyndrome.org



CLINICAL PRACTICE

**Avoidance of emergency surgery in newborn infants
with trisomy 18**

N= 7

A. P. BOS C. J. M. BROERS F. W. J. HAZEBROEK J. O. VAN HEMEL
D. TIBBOEL E. WESBY-VAN SWAAY J. C. MOLENAAR

“A newborn infant with trisomy 18 should be considered as a patient with a hopeless outlook who ought not be subjected to invasive procedures.”

“We believe that, because of their limited life expectancy or profound mental retardation, such patients ought to be transferred from the intensive-care unit and be allowed to die.”

“It is our experience that parents share our point of view, because they all want the best treatment for their children, which does not necessarily mean full intensive care.”

Trisomy 18: Compatible with Life

“Does ‘incompatible with life’ mean simply that they will not live beyond birth? That’s not true.”

Thomas Collins MD, Pediatric Cardiologist

“I believe this language is a self-fulfilling prophecy in medicine...So much literature has described these conditions as universally fatal, and we have let these children go for almost a generation.”

Danton Char MD

Pediatric Cardiac Anesthesiologist & Empirical Bioethics Researcher

Attitudes Toward Preterm Infants with a High Risk of Developing Long-term Disabilities



威爾斯親王醫院
Prince of Wales Hospital

Severe Global Disability Scenario:

Four limbs function poorly

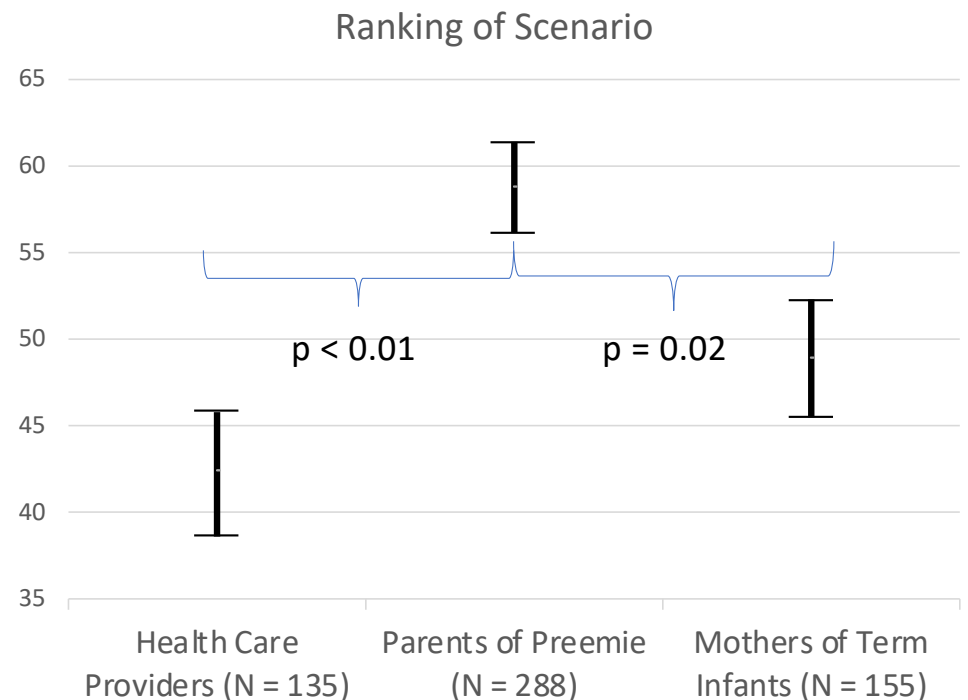
Unable to move around independently, mainly in bed or wheelchair

Intelligence equivalent to 1-yr-old

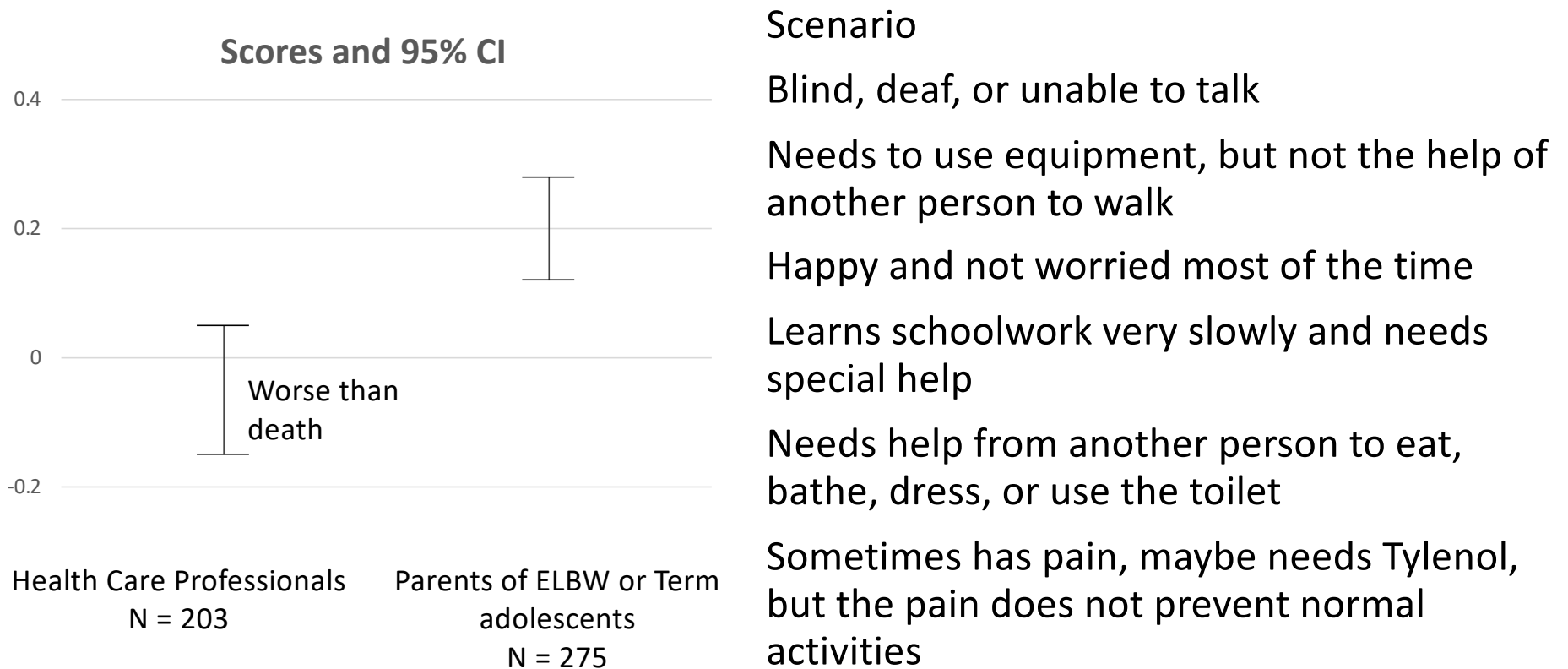
Unable to speak, read, or write

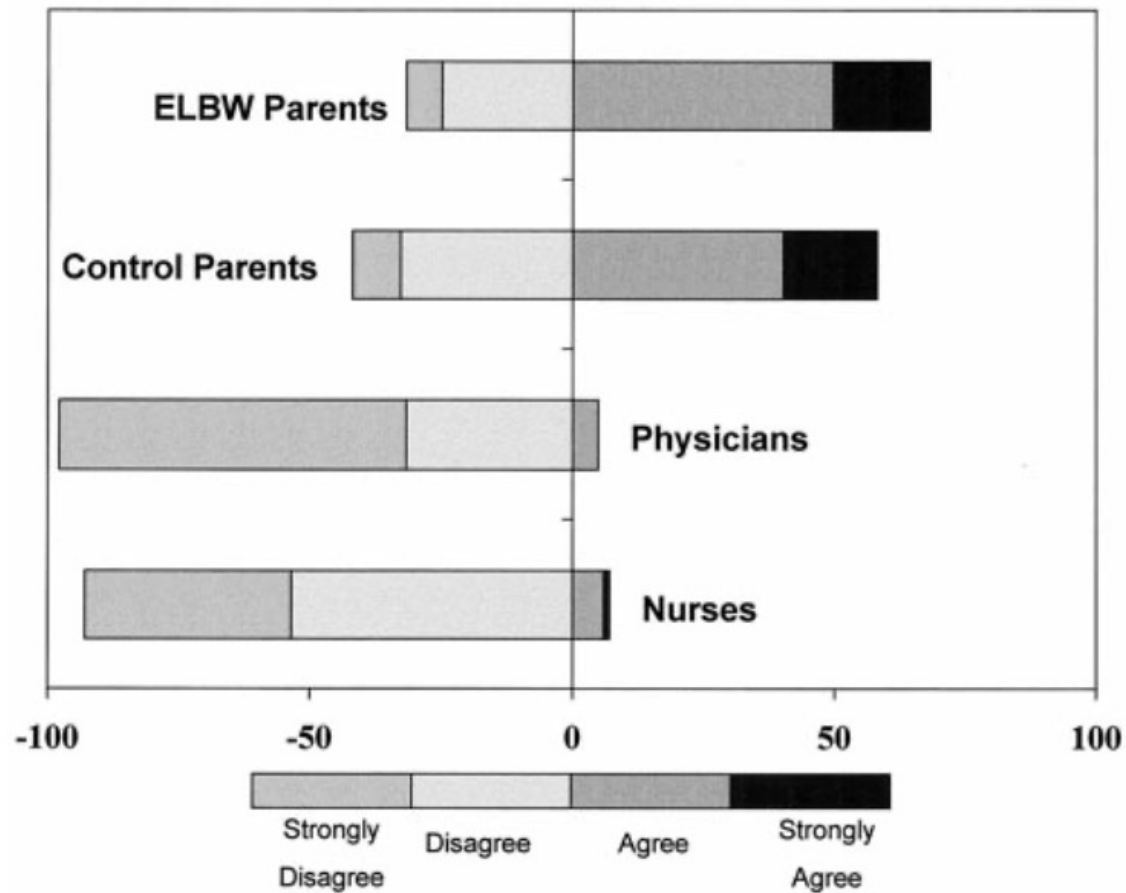
Daily activities of living entirely dependent on others

Urinary and fecal incontinence



Differences in Preferences for Neonatal Outcomes Among Health Care Professionals and Parents





N = 169

N = 123

N = 98

N = 99

Fig 3. Parents' and professionals' responses to the question, "I believe an attempt should be made to save all infants regardless of birth weight."



Race IAT

Race ('Black - White' IAT). This IAT requires the ability to distinguish faces of European and African origin. It indicates that most Americans have an automatic preference for white over black.

Weight IAT

Weight ('Fat - Thin' IAT). This IAT requires the ability to distinguish faces of people who are obese and people who are thin. It often reveals an automatic preference for thin people relative to fat people.

Gender-Career IAT

Gender - Career. This IAT often reveals a relative link between family and females and between career and males.

Religion IAT

Religion ('Religions' IAT). This IAT requires some familiarity with religious terms from various world religions.

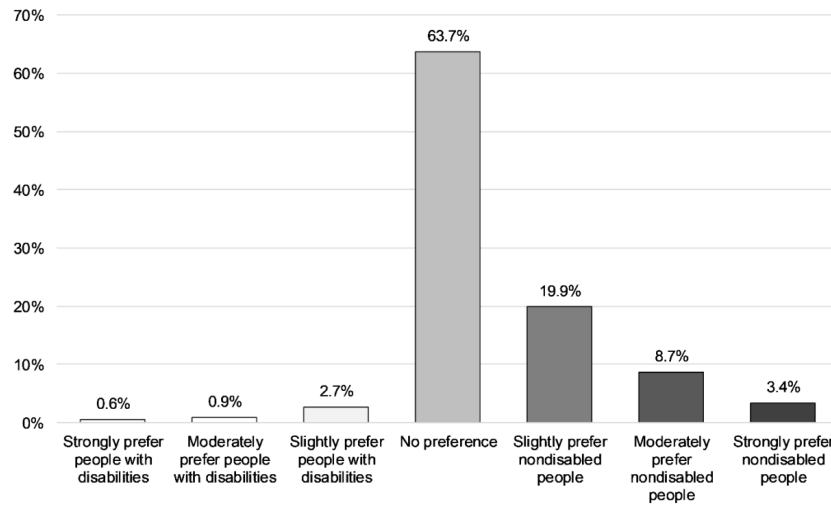
Sexuality IAT

Sexuality ('Gay - Straight' IAT). This IAT requires the ability to distinguish words and symbols representing gay and straight people. It often reveals an automatic preference for straight relative to gay people.

Disability IAT

Disability ('Physically Disabled – Physically Abled' IAT). This IAT requires the ability to recognize figures representing physically disabled and physically abled people.

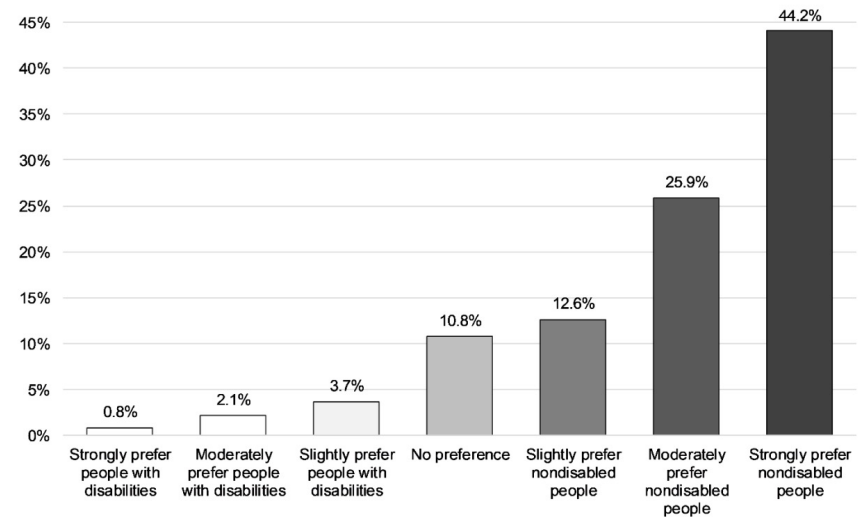
Explicit Attitudes of Healthcare Providers



32% Prefer
Nondisabled people



Implicit Attitudes of Healthcare Providers



82% Prefer
Nondisabled people



Resource Allocation Argument Does Not Justify “futility” or “incompatible with life”

Congenital anomalies “not compatible with life” are so rare

- Maximal treatment = Small % total health care budget

~3 million adults die in US/year
→ 1/3 admitted to MICU 6
months prior to death

30,000 infants die in US/year
(100x fewer deaths)

~40% MICU costs devoted to
patients who die before discharge

~8% NICU bed days devoted to
infants who die before discharge

Sachdeva et al. J Pediatrics 1996
Manzar et al. Saudi Med J 2005
Meadow et al. Acta Paediatrica 2012

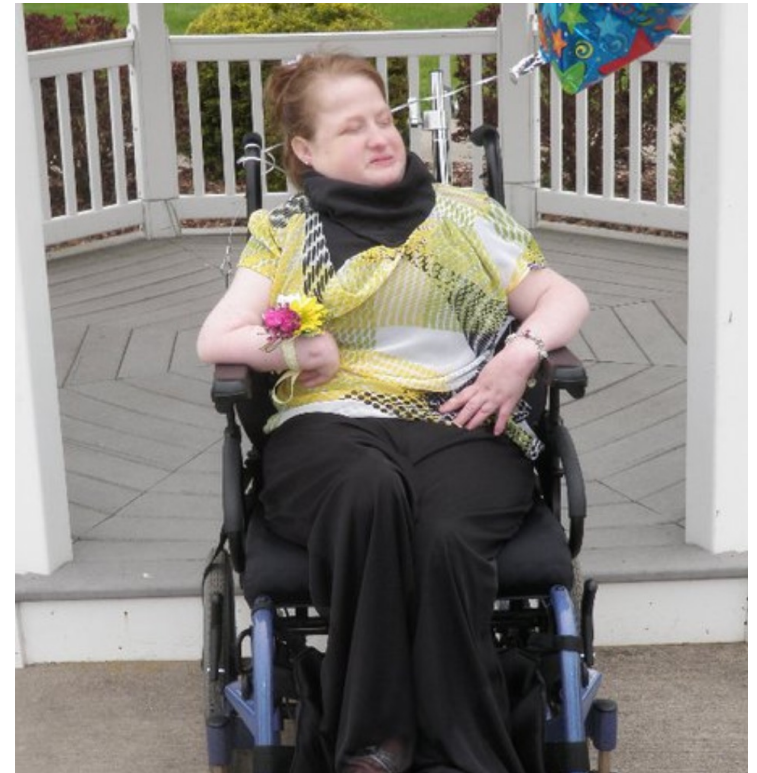
#3. “Not Compatible with Life” hurts families we serve

Words are “medically meaningless, incorrect, and enormously hurtful”

Tracy Harkin, mother of 8-year-old Kathleen Rose with Trisomy 13
Spokesperson for Every Life Counts (organization for patients with severe conditions)

Parent Reflections

Parents reported being told that their child:
was incompatible with life (87%)
would live a life of suffering (57%)
would be a vegetable (50%)
would live a meaningless life (50%)
would ruin their marriage (23%)
would ruin their family (23%)



Stacy Lynn VanHerreweghe
Rochester, NY, Trisomy 18, 5/21/1981

More Parent Reflections

“I think the ‘not compatible with life’ is not only terrifying to hear, but it’s not true. It’s incompatible with living to 40 years, but it’s not incompatible to life in general. It’s such a black and white statement that it gives you no hope at all...it’s a false statement.”

Mother, prenatal diagnosis Trisomy 18

Walker et al. J Perinatology 2008

“Projects a profound disregard for the child and the care that they and their families need”

Nora Sullivan MPA

Blog Post, The Term “Incompatible with Life” is Incompatible with the Best Care

Quotes from my Palliative Practice

“I have a fire in me that will never go away. It was the hardest thing to accept that 'Sorry, because of his extra chromosome, they won't do it (the surgery).' I wouldn't change anything. I went with what I felt I had to do. Everyone seemed against me. All I ask for is a chance, instead of saying, 'We can't.' He's one tough little guy. I feel so blessed to be chosen to be his Mom... I pride myself on being a good Mom.”

- Mom, 1 year old son with Trisomy 13

“I get emotional just talking about it now. It's been hard to get doctors that appreciate that his life is important and that he matters, having doctors that care.”

- Dad, 10-year-old son with leukodystrophy

Quotes from my Palliative Practice

"There's a difference in those in health care who have a passion for what they do. You can tell who is just there to do a job. You can tell by the chemistry you feel. To hear, 'This is all he is going to be able to do,' lets me know, we don't need to go any further [with that medical professional]. Small gains is a big gain for us. How can you say, 'This is it? How do you know?'"

- Mom, 18-year-old daughter with rare syndrome

Ethical Problems in Decision Making in the Neonatal ICU

John D. Lantos, M.D.

“The approach to shared decision making will not always lead to decisions that doctors or nurses would prefer. Sometimes, parents’ values are different from those of professionals. Such differences can lead to moral distress on the part of health care providers, especially nurses, who may find themselves required to deliver treatments that they find morally troubling. When decisions about treatment fall within the zone of parental discretion, however, parents’ preferences ought to prevail.”

Lantos JD. Ethical Problems in Decision Making in the Neonatal ICU. N Engl J Med. 2018 Nov 8;379(19):1851-1860.

What is Moral Distress?



When you feel you are unable to “do the right thing”

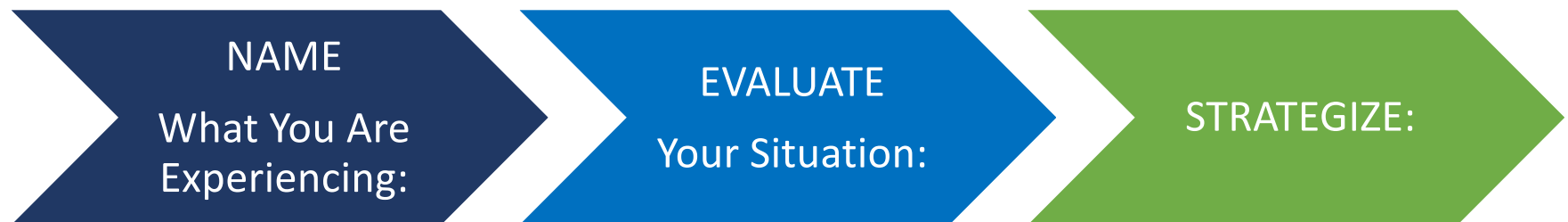
When you believe you are witnessing or causing suffering

When you feel you cannot meet the patient/family needs

When you are forced to prioritize certain values over other values

When you feel unsafe communicating your beliefs or values

Treat Moral Distress with Self Care & Reflection



Emotionally: anger, sadness, powerlessness, guilt

Physically: sleep deprivation, headaches, pain

Spiritually: grief, loss of meaning, decreased prayer/mediation

Psychologically: anxiety, depression

What are your values?

Past experiences with similar distress?

Barriers to action taking?

Self care

Identify boundaries

Debrief with perspective sharing



Let's Reflect

Now at the end of the session, you will:

Recall

The words, "Incompatible with Life" are rarely true, reflect our biases, & hurt the families we serve

Share

Stories of survivors: Trisomy 18 ([Megan](#)), Thanatophoric Dysplasia ([Charlie](#)), Renal Agenesis ([Abigail](#))

Recognize

Opportunities to educate other medical professionals: "It takes [courage](#) to look beyond the outdated textbooks"

“No matter what
people tell you, words
and ideas can change
the world”

- Robin Williams



Please give me feedback