15:56:36 . . . . . . .

Have.

15:56:39 >> Hello, everybody. And welcome. We are

15:56:41 going to begin in just one moment with a brief

15:56:46 overview of some of the controls for communicating and

15:56:49 participating in today's discussion. We'll see if any

15:56:54 other attendees will be joining us and we'll begin in

15:57:06 just one moment.

 So now that we have a few of

15:57:12 you with us now, we

did want to review just a few of the

15:57:15 communication

controls that we have for today's

15:57:21 session. So first

we want to remind everyone that we do

15:57:25 have ASL

interpreters on screen that will be

15:57:29 available on

screen for you should you need them.

15:57:34 We also have

CART captioning available. If you see

15:57:39 the bottom of

your screen, you will note a CC live

15:57:43 transcript icon

that will allow you to click on that

15:57:47 and follow along

with closed captioning as well.

15:57:50 One additional note that I want to provide you

15:57:54 is for the public chat function, that has been

15:58:00 disabled. So please do not use the chat function to

15:58:04 communicate with members of the panel. Instead we ask

15:58:10 that you use the icon that says Q and A. That Q and A

15:58:13 icon will allow you to provide any comments,

15:58:20 questions, or general feedback to the panelists. You

15:58:24 may do so and submit these questions anonymously, or

15:58:30 you can also indicate your questions yourselves,

15:58:35 whichever is your preference.

 One additional note that you

15:58:40 can also do, if you

click on participants at the bottom of

15:58:45 the screen, you

will also have the ability to raise

15:58:48 your hand. So if

you raise your hand, that will

15:58:54 indicate to the

moderator that you wish to speak and

15:58:59 once we recognize

you as a speaker, we will allow you to

15:59:04 speak to the

entire audience as part of this stage.

15:59:08

 So please just be sure to

15:59:12 unmute yourself if you

would like to participate in that

15:59:15 capacity and wait

for recognition from the moderator.

15:59:21 If you encounter any other issues, technical or

15:59:25 otherwise, you may insert those also into Q and A.

15:59:29 And we will try to address any concerns as best as we

15:59:31 can throughout the course of today's panel.

15:59:36 With that, beginning in perhaps just one more

15:59:40 minute, we'll turn things over to Dr. Kirschner to

16:00:09 begin.

 >> KRISTI KIRSCHNER: Welcome,

16:00:14 everyone. We're

going to get started. And I'd like to

16:00:17 first introduce

myself. I'm Kristy Kirschner. I'm a

16:00:21 disability

doctor. I'm also are the daughter of

16:00:25 an 86-year-old

woman who I've been advocating for and

16:00:30 helping to care

for during COVID. And a teacher. You

16:00:34 will see as we

introduce each of our panelists and

16:00:36 speakers that we

are going to use social roles and

16:00:40 identities in terms

of helping to contextualize our role

16:00:45 on this session.

 We welcome you to the third out

16:00:51 of four sessions

for our inaugural health equity and

16:00:55 ethic series,

transforming community conversations

16:00:58 about COVID-19

into action.

16:01:00 And for those of you who haven't been with us

16:01:06 since sections 1 or 2, let me just briefly review the

16:01:11 goals of our series. We're trying to -- to use the

16:01:14 foundation of the story, stories of injustice,

16:01:17 invisibility and health care to anchor the panels. We

16:01:20 want to try to look at these issues for multiple

16:01:24 viewpoints. And we want to focus the series on what

16:01:27 can we actually do. We don't want to just document

16:01:31 the problem. We want to look for real life solutions

16:01:36 that build on community strengths that are guided by

16:01:40 ethical values, and we want to bring together our

16:01:44 shared wisdom.

 Each of our panel structures

16:01:49 are roughly the

same. So you see the story as the

16:01:53 centrality of the

session. It will be a facilitated

16:01:59 dialogue with Mrs.

Hickson today, and I will introduce

16:02:03 Mr. Andres

Gallegos in a few minutes who will

16:02:04 facilitate the

conversation.

16:02:08 We also have experts from public health, ethics,

16:02:12 and law, health professionals that are helping to

16:02:18 inform the panel. So again this is the third session

16:02:22 out of four on covering disability bias and

16:02:26 discrimination in health care.

 We may be building on some of

16:02:29 the topics that we

discussed earlier, like this concept

16:02:32 of

intersectionality or social

16:02:37 vulnerability, which we

unpacked a little bit in our prior

16:02:40 session. Please

know that there are resources on the

16:02:44 website for these

sessions that you can look back and

16:02:47 review if you want

to learn more.

16:02:51 So this is our structure for today. I will

16:02:56 introduce each person in turn as we start the

16:03:01 conversation. As disclosures, I'm just wanting to

16:03:04 share with you these particular issues because they

16:03:10 will be pertinent to our panel discussion today.

16:03:15 For those of you who were with us on panel 1,

16:03:24 Dr. Rona hoe GART, a medical historian about race and

16:03:26 medical history gave us a little foregrounding to

16:03:28 prepare us for conversation and I'd like to do just a

16:03:32 little bit of that for today.

 What do we know about the

16:03:35 experience of

disability and medicine, and what do

16:03:37 we know

particularly about the deep roots of

16:03:41 bias and

discrimination. And I could go back

16:03:43 much further, but

I'm going to start with the history of

16:03:46 eugenics. The

late 1800s, started in Great Britain

16:03:50 but really got

its foot hold in the United States.

16:03:55 It was the idea

that we could use Darwin principles,

16:03:58 genetics to help

us breed better people.

16:04:01 And survival of the fittest, of course, was one

16:04:05 of the mantras. It merged into sort of these ideas of

16:04:08 social Darwinism which had nothing to do with

16:04:11 genetics. But it was a very popular movement in the

16:04:14 United States. And as part of that, we had certain

16:04:19 kind of negative eugenic forces, one being

16:04:22 sterilization of certain people who were considered

16:04:25 undesirable, including people with intellectual and

16:04:28 VENLT at disabilities -- and developmental

16:04:32 disabilities. In 1928 we had the buck versus bell

16:04:36 United States supreme court finding that three

16:04:43 generations of imbeciles are enough and allowed states

16:04:46 to have compulsory sterilization laws. And that

16:04:51 continued for some time.

 We also had other things going

16:04:54 on. And if you

look at the concept of

16:05:00 intersectionality, a lot of

eugenics was predicated on the Arian

16:05:03 race, on the

features and the characteristics of

16:05:07 white people. We

had fittest family contests taking

16:05:12 place at the

different state fairs. We also had

16:05:16 better baby

contests. And you would see pictures

16:05:19 like this in

magazines and publications.

16:05:25 But we also had a history of exclusion, of

16:05:28 isolation, of deprivation. And many people don't know

16:05:31 about the ugly laws. But in Chicago, for instance, we

16:05:36 had an ugly law that was just taken off the books in

16:05:41 1974. It's astonishing. And it read no person who is

16:05:46 diseased, made mutilated or in any way deformed so as

16:05:49 to be an unsightly or disgusting object or improper

16:05:54 person is to be allowed in or on the public ways or

16:05:58 other public places in the city or shall therein or

16:06:03 thereon expose himself to public view under a penalty

16:06:07 of not less than one dollar nor more than $50 for each

16:06:11 offense.

 So that's the ugly laws.

16:06:14 The picture on the right is a picture from

16:06:20 Willowbrook state school, and so institutionalization

16:06:22 was often the response to people born with

16:06:26 disabilities to people who had mental illness and they

16:06:31 were places that were very stark in terms of their

16:06:38 treatment of people. Geraldo RI VER a did an Expo say

16:06:42 of Willowbrook and Bobby Kennedy's remark was that

16:06:46 some of what he saw when he visited Willowbrook was

16:06:53 ivera did an Expo say

of Willowbrook and Bobby Kennedy's

16:06:53 remark was that

some of what he saw when he visited

16:06:53 Willowbrook was

that it was quote, unquote, like a

16:06:54 snake pit. So

history is really important. It's

16:06:56 part of our

culture. Now we're going to turn a

16:06:59 little more to the

medical system. And I want to talk

16:07:03 about these sort

of stark models. The medical model is

16:07:06 what is most

deeply embedded in our medical

16:07:11 history. You know,

that -- the disability is a tragedy.

16:07:14 It's always

negative. It's path logic and our

16:07:17 goal is to try to

cure or prevent or normalize the

16:07:23 individual. That it

always resides within the individual,

16:07:26 that we assume

that people with disabilities are

16:07:28 going to be

struggling with their emotional

16:07:32 adjustment to their

condition and the expert is always the

16:07:35 medical

professional. The medical

16:07:39 professional knows best.

 That is to be contrasted with

16:07:43 the very powerful

model that started with Michael Oliver

16:07:47 in Great

Britain again called the social model

16:07:49 where

disabilities is a difference as part

16:07:52 of our human

variation. And the stigma is the

16:07:58 result of our social

attitudes. It's a interactional

16:08:00 phenomenon between

the individual and society. The

16:08:03 solution is not to

change the body or the individual but

16:08:05 to change

society.

16:08:08 And in this model, the expert can be the person

16:08:11 and advocate or anyone else who changes the

16:08:14 relationship.

 We could go on for a long time

16:08:17 about models of

disability. There are many others.

16:08:22 But these are the

two that I think figure most

16:08:24 predominantly into our

session today.

16:08:28 We also have the history of human rights, which

16:08:31 I think informs our conversation. These are moral

16:08:34 frame works. World health organization after World

16:08:40 War II looked at human rights documents, and there was

16:08:44 a universal declaration of human rights. Eleanor

16:08:47 Roosevelt was one of the major forces behind this. In

16:08:50 fact, FDR had talked about a second bill of rights

16:08:55 before he died.

 We've got other human rights

16:08:59 documents, the most

pertinent for people with disabilities

16:09:04 is the

convention on rights of persons with

16:09:06 disabilities.

Now, these are very powerful

16:09:09 documents. They have

sort of worldwide effect. But the

16:09:13 United States has

not oftentimes ratified these

16:09:17 documents. And that's a

complicated topic that we could

16:09:20 discuss in another

place and time.

16:09:24 But the -- the convention on rights for people

16:09:28 with disabilities was in many ways modeled on our

16:09:32 civil rights laws. And so we started our disabilities

16:09:37 civil rights movement probably most robustly in the

16:09:40 '60s. Same time we were dealing with racial civil

16:09:44 rights, women's rights, civil rights was a very

16:09:47 important theme in the '60s. We were questioning

16:09:52 authority figures. And people, particularly those who

16:09:58 had grown up with polio, were at the forefront. Crip

16:10:04 camp, Judy human's new book are two great resources

16:10:06 for understanding a bit of this history. But these

16:10:10 are the major civil rights laws that we will

16:10:12 reference. Most importantly, the Americans with

16:10:17 Disabilities act in 1990 with the amendment in '98,

16:10:19 which will inform some of our conversation going

16:10:23 forward.

 So that is taking me up to

16:10:27 COVID. And like I

said, this is a whirlwind overview,

16:10:31 but then COVID

hit. So what did we learn? Were we

16:10:34 accessible? Had

we taken care of all the problems of

16:10:40 disability

attitudes and whatnot? Well, no, we

16:10:43 hadn't. And one

of the very earliest things that

16:10:46 happened with COVID

is we begin that people with

16:10:49 disabilities expressing

their discomfort with the conversation

16:10:50 that is were

happening.

16:10:54 Alice Wong is a wonderful person to follow,

16:10:57 disability visibility project. You can sign up for

16:11:00 her podcast. But she in this particular piece said,

16:11:05 you know, we know what it means to be vulnerable and

16:11:08 interdependent. We are the modern day oracles. It's

16:11:12 time people listened to us. Even before the

16:11:15 coronavirus pandemic, systems have always tried to

16:11:20 kill and oppress marginalized people. And she calls

16:11:23 out the attempts to repeal the affordable care act.

16:11:27 Human gene editing. While I was in California,

16:11:31 voluntary power shut offs by PG and E. You can see

16:11:35 Miss Wong use as ventilator. That's a big deal if

16:11:38 your electricity is turned off. Medicaid work

16:11:41 requirements, public charge rules. These crises and

16:11:46 assaults reconfirm who is disposable and unworthy of

16:11:48 assistance resource and attention and treatment. And

16:11:52 she says this time feels different for me with the

16:11:54 very real threats of health care rationing and

16:11:57 shortage of ventilators for critically ill patients in

16:12:01 the United States.

 So she's talking about the

16:12:03 conversations very

early on in the pandemic where we

16:12:07 didn't have enough

resources. We didn't know if we could

16:12:09 take care of

everybody who might need a ventilator.

16:12:11

 Then we began to talk about can

16:12:16 we take care of

everybody who's going into renal

16:12:20 failure. Do we have

did I at SIS machines. And then it

16:12:21 became

(Indiscernible) so we begin to have

16:12:24 these

conversations but how are we going to

16:12:27 decide who gets

the scarce resource. So one of the

16:12:30 things I would say

is very early on people with

16:12:32 disabilities learned

don't take anything for granted. They

16:12:36 felt at times

invisible. They weren't involved in

16:12:39 the pandemic

plans that they saw that were rolling

16:12:43 out. They felt

marginalized. Deprioritized, and

16:12:44 frankly

discriminated against.

16:12:50 So these crisis standards of care got a lot of

16:12:52 attention initially. You know, crisis standards of

16:12:56 care say okay, how are we going to create triage

16:12:59 algorithms to decide who gets the resource if we're in

16:13:02 a resource constrained condition. And almost

16:13:06 immediately as states began to publish their

16:13:10 guidelines, people with disabilities and their

16:13:15 advocates were charged in discrimination. People who

16:13:18 were older adults, people with disabilities were being

16:13:22 called out as deprioritized categories based upon

16:13:26 categorical exclusions, like people with severe

16:13:30 dementia, advanced and treatable neuromuscular disease

16:13:33 or people who might require assistance with activities

16:13:36 of daily living.

 Now, those complaints were

16:13:42 heard by the offices

of rice at HHS and very early on were

16:13:50 back in March

25th, 2020, Roger severino published a

16:13:53 bulletin that

reminded people of civil rights is

16:13:56 civil rights and

you don't suspend them during a

16:13:59 pandemic. Persons

with disabilities should not be denied

16:14:02 medical care on

the basis of stereotypes, assessments

16:14:04 of quality of

life or judgments about a person's

16:14:07 relative worth

based on the presence or absence or

16:14:11 age.

 So that was really helpful. We

16:14:15 had a very

strong statement. But then we have to

16:14:18 say okay, so

did that fix again all of the

16:14:22 problems? Well, we've

got very deep cultural roots. And I'm

16:14:25 going to

introduce this word ableism now. And

16:14:30 ableism is the

discrimination and social prejudice

16:14:31 against people

with disabilities based upon the

16:14:36 belief that typical

abilities are superior. And at its

16:14:39 heart, ableism is

rooted in the assumption that disabled

16:14:42 people require

fixing, defines people by their

16:14:46 disability. So all of

these ideas of fixing, curing,

16:14:49 normalizing that it's

the individual's problem, that we

16:14:51 should pity people

with disabilities, that the

16:14:55 appropriate response is

charity, that we have very low

16:14:59 expectations, people

with disabilities who grow up with

16:15:02 these attitudes may

internalize this oppressive sort of

16:15:06 thinking, feel

shame, isolate, be removed from

16:15:11 society, all of those

things are still present.

16:15:15 So we talked about OCR and crisis standards of

16:15:19 care. And OCR says you have to do individualized

16:15:24 assessment. No categorical exclusions. You've got to

16:15:28 look at the individual and their likelihood at medical

16:15:31 benefit and you cannot discriminate based upon these

16:15:34 characteristics. But we're still left with this

16:15:37 ableism and this idea of bias, both implicit and

16:15:41 explicit. And in reality, most decision making has an

16:15:45 involved crisis standards of care at all. Very rarely

16:15:48 have you seen them triggered, and I think it was four

16:15:51 states when I last looked, and it was for a very brief

16:15:54 periods of time. So decision making is taking place

16:15:58 at the bedside. So now we've got to say, okay,

16:16:00 individualized assessment is happening at the bedside,

16:16:03 but we're going to look at implicit bias and how that

16:16:05 plays a role.

 And we're also going to be

16:16:09 looking at just other

discrimination that we've seen, you

16:16:13 know, that we had

rigid visitors' policies rather than

16:16:16 view a visitor

for communication access or

16:16:21 information access, as a

reasonable accommodation, these rules

16:16:23 were created in

very rigid ways.

16:16:27 Hospitals were oftentimes not great with

16:16:29 disability access and accommodations before COVID.

16:16:33 They certainly didn't become more so after COVID.

16:16:37 We've had concerns and invisibility about people

16:16:39 who live in the home and require home and community

16:16:42 based services. How do we think about getting them

16:16:45 PPE. How do we think about protections and mitigation

16:16:49 of risk.

 People with disabilities,

16:16:52 particularly people

who have transportation difficulties,

16:16:56 there were lots

of questions about getting them

16:17:00 medical testing, COVID

testing, PPE, just access to basic

16:17:02 medical care,

particularly as outpatient clinics

16:17:05 closed. Public

health information was often not

16:17:09 successful. In fact,

the Trump administration had to be

16:17:12 sued because they

had no sign language interpreters in

16:17:15 their

informational sessions about COVID. .

16:17:18 And then we

have structural vulnerabilities and we

16:17:20 haven't

collected data about people with

16:17:23 disabilities.

 So that's where we are at this

16:17:27 moment in time.

And now we're going to turn it over to

16:17:33 Mr. Gallegos

who will facilitate our conversation

16:17:38 with Mrs. Melissa

Hickson who is the wife of Mr.

16:17:41 Hickson. She will

share her story about him and what

16:17:45 happened to him and

their family.

16:17:48 Mr. Gallegos identifies as a disability rights

16:17:52 attorney. He's an advocate, and he's also a person

16:17:58 with a disability. And Miss Hickson also identifies

16:18:02 as, of course, a wife, but a disability advocate and a

16:18:05 mother. And with that let me turn it over to

16:18:09 Mr. Gallegos.

 >> ANDRES GALLEGOS: Kristy,

16:18:13 thank you. I have

the privilege of introducing Mrs.

16:18:16 Melissa Hickson, the

widow of Mr. Michael Hickson and

16:18:20 mother to their five

children, ranging from ages 21 to 15.

16:18:22

 Melissa and Michael were

16:18:28 married for 18 years,

and on May 1, 2020, they celebrated

16:18:30 their 18th wedding

anniversary.

16:18:35 60 days later she presided over his cremation.

16:18:38 What you'll hear momentarily are the events and

16:18:42 circumstances that happened in between. This is a

16:18:47 story of profound ableism, an illustration of

16:18:50 discriminatory intentions dictating the course of

16:18:53 medical treatment, a story of both implicit and

16:18:58 explicit bias. A story that tragically is not the

16:19:02 only one of its kind, but is perhaps the most

16:19:07 egregious. I have to disclose that we're presently in

16:19:10 litigation in Texas state court against the entity

16:19:13 that was judicially appointed Mr. Hickson's temporary

16:19:16 legal guardian and who had legal authority over his

16:19:20 medical care at all relevant times that we'll discuss

16:19:23 here.

 As a result, we're not

16:19:27 providing specific

details about the guardianship matter,

16:19:29 although it had

a significant bearing on what

16:19:33 occurred.

 Our focus here is mainly to

16:19:36 discuss the conduct

and treatment provided by physicians

16:19:40 that cared for

Mr. Hickson. A lawsuit against them

16:19:43 in federal

district court in Texas is imminent.

16:19:46 Melissa, welcome and thank you for being here

16:19:49 with us.

 >> MELISSA HICKSON: Thank you.

16:19:51

 >> ANDRES GALLEGOS: Melissa,

16:19:56 share with us who

was Michael before May 24, 2017.

16:19:57 >> MELISSA HICKSON: So before that day,

16:20:01 Michael was a workaholic. He was a family man. He

16:20:08 was loved going to church, loved serving people, very

16:20:13 compassionate. Just a loving person that just always

16:20:16 wanted a family and just always put his family first

16:20:19 always.

16:20:20 >> ANDRES GALLEGOS: Melissa, what happened on

16:20:27 May 24, 2017?

 >> MELISSA HICKSON: It was a

16:20:30 day just like any

other day. We woke up that morning.

16:20:33 Michael got up,

fixed breakfast, got dressed. We

16:20:37 dropped the kids off

at school. And we had the one car, so

16:20:40 he was dropping

me off at work, and he just right as

16:20:45 we approached my

job, he passed out at the wheel. Now

16:20:49 what I know is

he went into sudden cardiac arrest at

16:20:54 that time and he

was taken to the hospital.

16:20:56 >> ANDRES GALLEGOS: And as a result of the

16:21:00 sudden cardiac arrest, he developed a number of

16:21:04 complex disabilities. The deprivation of oxygen

16:21:10 resulted in a brain injury. Melissa, what was the

16:21:13 effects of that injury?

 >> MELISSA HICKSON: So -- and

16:21:17 you're correct.

So he was -- he was basically died

16:21:23 twice within an

hour. He was resuscitated in -- and

16:21:27 months later we

found out that he couldn't see. We

16:21:32 also found out, of

course, that he did have an aknocksic

16:21:35 brain injury.

We found that out early, that there

16:21:39 was an anoxic

brain injury and told that his chances

16:21:42 of survival

were not good, that we should probably

16:21:45 end his life,

that he would never be the same person

16:21:49 or have the

same personality again.

16:21:55 >> ANDRES GALLEGOS: So not only did he have

16:21:58 anoxic, but as a result of the CPR they had to utilize

16:22:02 to sustain his life, he also ended up having a severe

16:22:06 spinal cord injury resulting in quadriplegia. What

16:22:10 was his result to function with the quadriplegia?

16:22:11 >> MELISSA HICKSON: So initially he couldn't

16:22:15 function at all. He at some point did reFWAN some

16:22:18 function in his arms and hands. He was able to grip a

16:22:22 gain some

function in his arms and hands. He

16:22:24 was able to grip a

wash cloth or hold my hand. So those

16:22:27 were some of the

things that he could do. He was --

16:22:30 when he finally

went to rehab, he was able to kind of

16:22:37 assist with

transferring by holding onto the bed

16:22:40 and with his

sight as well, he had kind of glimpses

16:22:43 of different

shapes, different things pretty early

16:22:48 on. But then

that faded about six months later.

16:22:49 >> ANDRES GALLEGOS: So Michael did need

16:22:53 assistance with activities of daily living and you

16:22:55 received that from you and from the kids when you were

16:22:57 with him.

 >> MELISSA HICKSON: That's

16:23:00 correct. So he

did. At home he did receive

16:23:02 assistance from myself

and the kids as well.

16:23:04 >> ANDRES GALLEGOS: So immediately after the

16:23:08 sudden cardiac arrest, Michael was initially treated

16:23:11 at a hospital in the Dallas area where he stayed

16:23:13 approximately just a couple of days. And from there

16:23:17 he was transferred to a real rotation hospital in

16:23:20 Houston. He came home for a little bit. Then he was

16:23:24 admitted to another post acute specialty hospital for

16:23:26 rehabilitation. He stayed there for more than 12

16:23:30 months for extensive rehabilitation therapy.

16:23:32 Melissa can you describe for us what Michael's

16:23:36 ability was to communicate and to be present?

16:23:38 >> MELISSA HICKSON: Well, he was always able

16:23:44 to communicate. Weeks after the cardiac arrest, he

16:23:47 began by blinking and the next thing was shaking his

16:23:51 head. He progressed into laughing. And then we

16:23:53 realized at some point he began to talk. The first

16:23:57 thing that he did was say bye to his youngest sister.

16:23:59 So from there he was able to respond to questions. He

16:24:02 was able to answer trivia questions. He was able to

16:24:06 say what he wanted if he was cold or hot. He was able

16:24:09 to play games and talk to my kids and kind of get on

16:24:14 their case about school and their birthdays. Every

16:24:20 year he sang happy birthday to each of our children.

16:24:23 >> ANDRES GALLEGOS: Melissa, after Michael's

16:24:26 accident, you took on a new role, in addition to being

16:24:29 Michael's best friend and wife, you became his patient

16:24:31 advocate. What prompted you to do that and what did

16:24:34 that entail?

 >> MELISSA HICKSON: Well, I

16:24:39 became his patient

advocate days after he went into

16:24:41 sudden cardiac

arrest. And mainly because of the

16:24:45 initial neurologist

telling us that his prognosis wasn't

16:24:47 good and he

wouldn't make it. He probably would

16:24:49 never be the same

person again. I knew at that point

16:24:53 that it was going

to be fighting an uphill battle. I

16:24:56 saw early on that

they pretty much had just dismissed

16:24:59 him, that

according to them, his life was over,

16:25:02 he would never

be the same. And then when I saw him

16:25:04 slowly coming

out of it and being able to respond

16:25:09 and do things, I

saw that there was more than they had

16:25:13 told me was

going to be there for him. And it was

16:25:16 -- it was an

uphill battle. They did not want to

16:25:19 give him

rehabilitation. They didn't want to

16:25:21 believe that

there was any possibility that he will

16:25:25 be able to

function or live a life of quality

16:25:30 ever. So I did. I

had to fight everywhere along the way

16:25:36 for services,

for medications, for supplies, for

16:25:40 them to actually

see the possibility in him of being

16:25:45 able to live a

full life.

16:25:47 >> ANDRES GALLEGOS: In June 2017 in order to

16:25:50 get access to certain of Michael's accounts that were

16:25:54 only in his name, Melissa had to apply to be his

16:25:58 guardian. During the process of applying for

16:26:01 guardianship, family members of the ward, the person

16:26:05 for whom guardianship is being established, have an

16:26:08 opportunity to challenge the petition or waive their

16:26:12 rights to challenge.

 Michael has three sisters, one

16:26:16 of which is a

doctor. Two of the sisters signed the

16:26:20 waivers. His

physician sister did not. Instead she

16:26:24 filed her own

petition to assume guardianship over

16:26:28 Michael. As a

result, Melissa was in a contested

16:26:32 guardianship

proceeding. Now, between 2017 and

16:26:37 2019, Michael was

in and out of hospitals and

16:26:42 rehabilitation facilities.

In August 2019, Melissa relocated the

16:26:48 family from

Dallas county to Travis county, the

16:26:52 Austin area. And

when she relocated, that caused her to

16:26:56 have to start

over again with a new petition for

16:27:01 guardianship in

Travis county. The court in Travis

16:27:04 then appointed a

special guardianship service to serve

16:27:07 as Michael's

temporary guardian, as there was a

16:27:09 contested

guardianship proceeding.

16:27:13 At the end of 2019 and beginning of 2020,

16:27:17 Michael had multiple hospitalizations for reoccurring

16:27:21 urinary tract infections, sepsis and pneumonia, which

16:27:24 unfortunately occurs with great frequency to persons

16:27:29 with extensive disabilities that Michael had. Persons

16:27:33 sustaining high levels of spinal cord injuries are

16:27:39 susceptible to autonomic disreflexia which causes

16:27:42 chronic autoimmune suppression that leaves them more

16:27:45 susceptible to infections which if not properly

16:27:48 treated can lead to ultimate untimely death.

16:27:52 In fact, in February and March 2020, Michael was

16:27:55 admitted to a hospital in Austin for treatment of

16:28:00 double pneumonia, sepsis and urinary tract infection.

16:28:03 Is that correct, Melissa?

 >> MELISSA HICKSON: That is

16:28:05 correct.

 >> ANDRES GALLEGOS: And was he

16:28:06 treated

successfully?

16:28:08 >> MELISSA HICKSON: Yes, he was.

16:28:10 >> ANDRES GALLEGOS: Now, in May, Michael was

16:28:13 at a nursing facility in Austin where he tested

16:28:15 positive for COVID-19 but was diagnosed as

16:28:19 asymptomatic, is that correct?

 >> MELISSA HICKSON: That's

16:28:22 correct.

 >> ANDRES GALLEGOS: In early

16:28:25 June, June 2 to

be precise, Michael was admitted to

16:28:28 the same hospital

again because of pneumonia, urinary

16:28:32 tract infection,

sepsis, and suspected COVID-19 similar

16:28:35 conditions for

which he was successfully treated at

16:28:38 that very

hospital months earlier.

16:28:42 Melissa, when Michael was admitted within the

16:28:46 first hour that he was triaged by a hospital emergency

16:28:49 room doctors, what happened?

 >> MELISSA HICKSON: Yeah,

16:28:53 within hours of

triage, they made a decision that

16:28:58 treating him would

be futile based on his disability.

16:29:02 And they set in

motion at that point quick placing him

16:29:05 in hospice

care.

16:29:07 >> ANDRES GALLEGOS: In fact, what they said is

16:29:10 that the compassionate thing to do was provide him

16:29:14 comfort care and render him do not resuscitate, is

16:29:16 that accurate?

 >> MELISSA HICKSON: Yes.

16:29:18 >> ANDRES GALLEGOS: Melissa, when we look at

16:29:22 the medical records, from the emergency room doctor to

16:29:25 his hospitalist, it was clear that Michael's quality

16:29:28 of life came into question from the moment that he

16:29:32 arrived and there was an emphasis to change his status

16:29:37 from full code to do not resuscitate.

 What were your discussions with

16:29:40 his guardian and

the doctors regarding the change of

16:29:44 code status?

 >> MELISSA HICKSON: So the

16:29:50 code status was

always full code. It was discussed at

16:29:53 the time that

he was actually diagnosed with COVID

16:29:57 in May. Full

code. I was asked again what the

16:30:01 status would be, and

I did also respond again that it

16:30:03 should remain full

code.

16:30:07 I didn't find out that they changed it until

16:30:11 three days into the hospital. And that was the day

16:30:14 that I spoke with the doctor in the hallway. And he

16:30:19 let me know that treating him would be futile because

16:30:24 he could not walk and talk.

 >> ANDRES GALLEGOS: Melissa,

16:30:27 did Michael have

an advanced directive?

16:30:29 >> MELISSA HICKSON: No.

 >> ANDRES GALLEGOS: How did

16:30:32 you know what his

end of life preferences were I will.

16:30:34 >> MELISSA HICKSON: Well, we had discussions

16:30:35 not specifically about what his end of life

16:30:38 preferences were. We were both in our 40s, didn't

16:30:41 really think about that kind of plan. But the

16:30:44 discussions we had before were always that he just --

16:30:50 he loved life. He had had other relatives on his

16:30:53 mother's side of the family that suffered from mental

16:30:56 illness and committed suicide, and he always talked

16:30:58 about them and would say that he just -- he would

16:31:01 never do that. He loved life. He wanted to grow old

16:31:05 with me and being able to see his grandchildren.

16:31:08

 >> ANDRES GALLEGOS: Melissa,

16:31:10 you had an

opportunity to visit Michael in person

16:31:13 and through

face time the first couple days that

16:31:16 he was in the

hospital. Was Michael responsive to

16:31:18 you?

 >> MELISSA HICKSON: He was.

16:31:21 We went to visit

him three days after he was admitted

16:31:25 when he was in

ICU and a friend and I did face time

16:31:30 with him on her

phone and I think the hospital, we did

16:31:33 the children in

the room with him and then outside the

16:31:36 room with me.

And he was responsive. They were

16:31:38 telling him about

how they were doing in school and that

16:31:42 they loved him

and I also did -- I prayed with him

16:31:45 and I asked him,

you know, to -- as we always did at

16:31:48 the end of the

visit, I would say give me a kiss.

16:31:52 And under the

(inaudible) you could see him pucker

16:31:55 his lips and the

nurse was like oh, that's so sweet.

16:31:58 But he was

very -- he was responsive, I mean, as

16:32:01 responsive as

you could be with a biPap machine on

16:32:05 your face but he

nodded his head and puckered his lips

16:32:09 and shook his

head to respond to the kids.

16:32:11 >> ANDRES GALLEGOS: Between his admission on

16:32:14 June 2 through June 5, Michael's health fluctuated.

16:32:19 He showed evidence of quickly responding to

16:32:23 antibiotics but intermittent saturation of oxygen for

16:32:29 which he needed more oxygen via a can LA and by pop

16:32:33 machine. Michael feeding through a gastrostomy tube,

16:32:37 a process he used since March 2018. He required

16:32:42 periodic moderate assistance to clear secretions which

16:32:45 helped his condition. He was experiencing high

16:32:51 fevers, antibiotics were provided to treat his

16:32:54 underlying infections and improvement in his symptoms.

16:32:58 Then with no explanation in the medical record, his

16:33:05 attending physician abruptly stopped the.

16:33:08 Antibiotics. A decision was to change his code from

16:33:12 full code to DNR and withdraw all life sustaining

16:33:17 treatment including artificial nutrition and

16:33:19 hydration.

 Melissa, on June 5, you were

16:33:22 able to see

Michael. This is the same day this

16:33:24 decision was made.

And you spoke to his doctors. You

16:33:28 were there with a

family friend. And as the three of

16:33:32 you were talking

with Michael's doctor, your friend

16:33:38 recorded the

conversation. Kristi, if we can hear

16:33:43 the

conversation.

16:34:56 >>

 >> Correct.

16:34:58 >> Who gets to make that decision whether

16:35:00 somebody's quality of life, if they have a

16:35:03 disability --

 >> KRISTI KIRSCHNER: I'm

16:35:07 sorry, folks. I

understand -- let me start back again

16:35:08 at the

beginning. I'm sorry. I didn't have

16:35:17 -- I was muted.

 >> Right now the criteria is

16:35:20 requiring

intubation, so if you wanted then you

16:35:22 would be

(inaudible). But at this point with

16:35:27 the -- with the

decision is do we want to be extremely

16:35:30 aggressive with

his care or do we want, do we feel

16:35:34 like this will be

futile? And the big question of

16:35:38 futility is one that

we always question. And the issue is

16:35:41 will this help

him improve his quality of life? Will

16:35:44 this help him

improve anything and will it

16:35:49 ultimately change the

outcome? And the thought is -- the

16:35:51 answer is no, to

all of those.

16:35:53 >> MELISSA HICKSON: What would make you say

16:35:56 there is no probability.

 >> Because as of right now his

16:35:59 quality of life,

he doesn't have much of one.

16:36:03 >> What do you mean? Because he's paralyzed

16:36:06 with a brain injury he doesn't have quality of life?

16:36:11 >> Correct.

 >> Who gets to make that

16:36:14 decision whether

somebody's quality of life, if they

16:36:17 have a disability

that their quality of life is not

16:36:19 good?

 >> So it's not me. I don't

16:36:25 make that decision.

However, it's -- will it affect his

16:36:27 quality, will it

improve his quality of life? And the

16:36:31 answer is no.

 >> Would you be able to live

16:36:34 isn't improving

his quality of life.

16:36:38 >> There is no improvement. Being on a

16:36:41 ventilator for more than two weeks. Each of our

16:36:45 people here have COVID and have been here for more

16:36:48 than two weeks. So they're basically on the

16:36:53 ventilator till they die?

 >> If I were to be frank, yes.

16:36:55

 >> So if somebody doesn't die,

16:36:57 are you going to

(inaudible).

16:37:00 >> So I can count with one hand the three

16:37:05 patients that have made it through.

 >> You can count three?

16:37:07 >> Correct. Correct. Exactly. I'm not -- I

16:37:10 get your point. There are three. However, he doesn't

16:37:13 fit those three. Those three are young people that

16:37:16 don't have medical problems. This guy is young, but

16:37:20 he has a number of medical problems.

 >> So just so you know, my

16:37:25 uncle is 90 years

old. He got COVID. And he has a

16:37:27 bunch of medical

problems. He has cancer.

16:37:29 >> Well, I would consider that a blessing every

16:37:32 minute that he's still alive. A blessing.

16:37:34 >> Which is why to me you can't say that,

16:37:37 though, because all the directions pointed to him as

16:37:41 being high risk, that he wouldn't make it. And he

16:37:45 did. Why would somebody pass away when he' younger

16:37:47 than him.

 >> Well, I'm going to go with

16:37:51 the data, I don't

go with stories. Stories don't help

16:37:53 me.

 >> So did those three that made

16:37:54 it, did they

get --

16:37:57 >> They did not.

 >> No? They just -- they

16:37:59 fought it on their

own?

16:38:00 >> Correct.

 >> With oxygen.

16:38:03 >> With oxygen.

 >> And how long were they here?

16:38:05

 >> Probably about one and a

16:38:09 half to two weeks,

probably longer. So.

16:38:11 >> So he's --

 >> Right. However, his quality

16:38:14 of life is

different from theirs. They're

16:38:16 walking and talking.

 >> He can't walk now.

16:38:21 >> Right. And I don't mean to be frank or

16:38:26 abrasive or anything, but at this point we are going

16:38:29 to do what we feel is best for him along with the

16:38:33 state and this is what we decided.

 >> So the fact that you're

16:38:35 killing someone

doesn't make sense in your mind.

16:38:38 >> We don't think it's killing. Because I

16:38:41 don't know when or if he'll die but I do think.

16:38:44 >> Well, we're all going to die at some point.

16:38:47 >> Right. Exactly. You're right. We all are

16:38:50 going to die. So I don't know when or if he will die,

16:38:55 but at this point I don't think it would be humane or

16:38:58 compassionate to put a breathing tube in this man and

16:39:01 do the lines and tubes and all that stuff and I don't

16:39:04 think it would benefit him.

 >> I totally agree with you on

16:39:07 the intubation

part. I don't want him to be. But I

16:39:09 also don't think

that you should just sit him somewhere

16:39:12 to be

comfortable until he finally just

16:39:13 drifts away.

 >> Right.

16:39:16 >> That to me is futile too because that's

16:39:19 saying that you're not trying to save somebody's life.

16:39:22 You're just watching them go away, the ship is

16:39:25 sailing. I mean, that doesn't make any sense to me to

16:39:30 not try. I don't get that part.

 >> Right. And it's not -- it's

16:39:33 not easy. None

of these things are easy. And this is

16:39:36 a calculated

decision. And we feel like this is

16:39:40 what's going to be

best for him. Okay? So if this was

16:39:42 your spouse, you

would be okay.

16:39:45 >> I would totally do this if this was my mom,

16:39:49 my dad, my sister, my spouse. You can call me a liar,

16:39:52 you can do whatever you want, but this is how I feel

16:39:54 and I've seen this certainly more than you have. I've

16:39:57 seen people die.

 >> You've seen it more but you

16:39:59 haven't felt it

like this --

16:40:00 >> You don't know anything about me.

16:40:05 >> And you don't know about me.

 >> Okay. This is hard. But

16:40:07 let's relax.

 >>

16:40:10 >> Right the I'm not saying that I do. But

16:40:13 what I'm going to tell you is this is a decision

16:40:15 between the medical community and the state.

16:40:18 >> Forget about the wife and his family and his

16:40:27 five kids.

 >> It has nothing --

16:40:29 >> ANDRES GALLEGOS: It would be futile to

16:40:32 treat him.

 >> Good afternoon. Welcome to

16:40:36 another COVID

themed medical grand round. I'm Dr.

16:40:39 Chair of the

department of medicine at UCSF. The

16:40:42 title of

(inaudible) is the fourth way in, is

16:40:45 it safe to fill

in the blank. You see the

16:40:50 instructions here for this

conference. If you have questions,

16:40:53 please type them

in the Q and A box and we'll link it

16:40:57 to captioning.

 >> Sorry.

16:40:58 >> ANDRES GALLEGOS: It would be futile, the

16:41:02 doctor said. Nothing he would do would result in any

16:41:06 benefit. He didn't say that it would benefit

16:41:11 Michael's sepsis, the pneumonia, the urinary tract

16:41:14 infection. It simply would not make him walk and

16:41:17 talk. And the patients that he was treating for a

16:41:20 suspected COVID, they could walk and they could talk.

16:41:23 Melissa, what were you thinking at the moment

16:41:27 that you heard that and how could you remain so calm?

16:41:31 >> MELISSA HICKSON: Well, I was in disbelief

16:41:35 that first of all, that he was speaking to me that

16:41:39 way. That was the first thing. And the second thing,

16:41:42 of course, the words that were coming out of his

16:41:45 mouth. I couldn't understand how someone who has

16:41:51 taken a vow to save people's lives could put him

16:41:58 pretty much in a category of untreatable, unsaveable,

16:42:02 unhuman. And I -- you know, it's funny listening to

16:42:04 it, I started thinking back to that conversation with

16:42:10 him and how I felt, like he pretty much stripped me of

16:42:18 any type of humanity. It's bad enough when your life

16:42:22 is taken away unnecessarily. But to speak to someone

16:42:34 the way he spoke to me, I can't even begin to tell you

16:42:37 how that felt. You asked me how I was able to stay

16:42:45 calm, and it was for the reason the guardianship and

16:42:49 a(inaudible) was taken from me because -- and I was

16:42:52 going to do this and that and advocated for him. It

16:42:55 was because I advocated so hard for him to make sure

16:42:58 he got what he needed and that was called into

16:43:05 question. So it was -- I was actually -- my friend

16:43:08 and I actually were directed upstairs by a security

16:43:19 officer which had been called for us to be guided

16:43:22 upstairs and the security officer remained there and

16:43:24 sat there during our conversation with the doctor in

16:43:27 the hallway. After that conversation was over, he

16:43:33 walked us out to the parking lot, not just downstairs,

16:43:36 to the front desk. He walked us out to the parking

16:43:45 lot. I will never -- that was extremely hurtful. It

16:43:50 really was.

 >> ANDRES GALLEGOS: Melissa,

16:43:52 what happened

over the last six days of Michael's

16:43:56 life when he was

in the hospital?

16:44:00 >> MELISSA HICKSON: So over the next six days,

16:44:04 I spent -- actually from the moment I left the

16:44:07 hospital that day, I began to make calls. I tried to

16:44:10 find any and everyone I could to try to help to

16:44:13 intervene, to try to get a restraining order, to try

16:44:17 to get another guardianship attorney to help me. I

16:44:21 tried to reach out to the attorney that was involved

16:44:24 with the case. I did everything I possibly could and

16:44:29 looked everywhere to try to find somebody to help, to

16:44:34 hear me, to actually see the situation and intervene,

16:44:38 to stop what they were doing. And to begin treating

16:44:43 him. During those days, I asked for based on business

16:44:46 they never called me back. I called every single day.

16:44:50 They never called me back to do a face time visit with

16:44:54 him. And that lasted up until the day that he passed

16:44:58 away. In fact, the morning after he passed away, I

16:45:03 called to get a face time visit with him, and they

16:45:05 didn't tell me that he had passed away the night

16:45:12 before.

 >> ANDRES GALLEGOS: Melissa,

16:45:14 going back to the

conversation you had with the doctor

16:45:18 on June 5 that we

just listened, how should have that

16:45:21 conversation went

between you and him?

16:45:26 >> MELISSA HICKSON: He -- the conversation --

16:45:28 and this is how I thought the conversation was going

16:45:32 to go when I approached him. I thought that he was

16:45:36 going to give me the -- you know, just typical,

16:45:38 because again we've been in and out of the hospital I

16:45:41 don't know how many times. I've never had the issue

16:45:43 before. Usually the doctor would tell you what's

16:45:46 going on, what they're doing to treat him. And ask

16:45:51 for any input. None of that happened. I thought that

16:45:54 I was going to have an opportunity to talk to the

16:45:58 doctor about what the treatment plan was. I just

16:46:02 assumed there would be a treatment plan. So it was a

16:46:05 shock to me to find out the treatment plan there was

16:46:10 there was no treatment plan.

16:46:12 >> ANDRES GALLEGOS: Melissa, we have a

16:46:14 significant number of medical students and medical

16:46:18 professionals listening. What's your message to them?

16:46:22 Now, let me correct that. What is your PG rated

16:46:27 message to them?

 >> MELISSA HICKSON: Well, it's

16:46:30 PG rated

because they didn't do this to me.

16:46:34 But what I'd like

them to take away from this is that

16:46:40 you don't know the

whole story about people. And to make

16:46:43 an assumption

based on what you think you know is

16:46:46 never a good

thing. And, you know, I've always

16:46:50 been taught what

you do when you assume. And in this

16:46:53 case to me, I

think he assumed that he knew who I

16:46:57 was. And he

didn't. He did not treat me like a

16:47:00 human. He did not

treat me like a wife of 18 years that

16:47:05 fought for her

husband every bit of every single day

16:47:09 over the past

prior three years. I've lost jobs.

16:47:14 We've been

homeless, we moved. I mean, all of it

16:47:17 so he could get

the medical treatment. I've not had

16:47:22 medical care for

myself to pay his premium so that he

16:47:26 could maintain

coverage. So this person that's

16:47:30 talking to me in the

hall is treating me like I'm not

16:47:35 human, and I don't

deserve to be treated as human was so

16:47:39 wrong. . He was

so wrong. And for those medical

16:47:42 students, just know

that the person that you're talking to

16:47:45 is human. They

have feelings. The person that they

16:47:49 love is in that

room. And there's nothing more that

16:47:53 they want but for

that person to get better. So you

16:47:56 kind of have to

understand their perspective and not

16:48:01 come at them with

what the data shows. You know, you

16:48:04 heard him say I

don't care about stories. All I care

16:48:07 about is data.

But I'm not data. My husband's not

16:48:12 data. He's a

person. And it's really important to

16:48:15 treat people as

if they're human and they're people

16:48:17 with feelings and

they love that person. So I would

16:48:20 tell you to treat

them as human first. Don't come in

16:48:26 with any type of

preconceived notions about the person

16:48:29 until you talk

to them.

16:48:31 >> ANDRES GALLEGOS: Melissa, did the hospital

16:48:34 administrators that are with us, what's your message

16:48:38 to them?

 >> MELISSA HICKSON: This one

16:48:40 you want PG rated

as well?

16:48:42 >> ANDRES GALLEGOS: Yes, ma'am.

16:48:46 >> MELISSA HICKSON: My message to the hospital

16:48:49 administrators, I really don't have one. Just, you

16:48:52 know, I had a really bad experience. This isn't the

16:48:55 first time with hospital administrators. And again, I

16:48:58 mean, you know, I understand they have jobs to do.

16:49:02 But they also need to treat people as human as well

16:49:05 and not as a number. And not as data and not as a

16:49:09 number on their budget, their fiscal year, or what

16:49:13 they look like as far as the number of discharges.

16:49:15 People are patients and families are more than just

16:49:22 that. And they do need to also see them as humans.

16:49:24 >> ANDRES GALLEGOS: And finally, Melissa, to

16:49:30 the spouses, the mothers, the fathers, of persons with

16:49:33 complex disabilities who may find themselves in a

16:49:35 similar situation that you were in back in the middle

16:49:39 of June last year, what's your message to them?

16:49:42 >> MELISSA HICKSON: My message to them is

16:49:47 don't give up. And I say that because, you know --

16:49:49 and I've said this to people actually recently about

16:49:52 the fact that I feel guilty in some respects that I

16:49:55 didn't do more. But the truth is I couldn't have done

16:49:59 more. And I know that. But I will say for those

16:50:04 people to keep fighting. Just to keep fighting,

16:50:08 advocate, pushing, looking, searching, talking,

16:50:11 whatever it is, that you need to do to get help for

16:50:18 that person. . Don't stop.

 >> ANDRES GALLEGOS: Melissa, I

16:50:20 want to thank

you. I know this was difficult to do

16:50:23 but your voice

is powerful and needed to be heard.

16:50:33 Thank you.

Kristi?

16:50:35 >> KRISTI KIRSCHNER: Yes, thank you, Mrs.

16:50:42 Hickson, and thank you Andres.

 As you know, Miss Hickson, we

16:50:45 have panelists

that we've invited who will now

16:50:50 provide some

reflections, some thoughts about the

16:50:55 situation we find

ourselves in in health care right now

16:50:58 as well as the

story you've just shared.

16:51:05 I'm going to turn first to Dr. Ann Jackson who

16:51:08 identifies herself as a learner, as a neighbor, a

16:51:15 teacher, a caregiver, an advocate and friend. Dr.

16:51:24 Jackson.

 >> ANN JACKSON: I want to add

16:51:27 to my

description first, and I want to add

16:51:36 wife of a man, of

almost 30 years, and so I -- so I'm

16:51:42 going to bring

that lens to this too. And I'm going

16:51:45 to start, Miss

Hickson, by acknowledging you as a

16:51:49 queen, and I'm

going to acknowledge him as a king.

16:51:53 And I'm going to

acknowledge both of you as people who

16:52:01 come from a very

rich heritage, people who often are

16:52:04 thought to be more

resilient than they are but people of

16:52:09 color, people

from the African diaspora. We are

16:52:12 delicate. We are

delicate flowers, and to your point,

16:52:16 we are human,

right? We are human. We are fully

16:52:20 human. And in

that regard, we deserve the highest

16:52:23 respect and

accolades that any human deserves. So

16:52:27 let me first

again acknowledge you for the queen

16:52:32 that you are.

 So queen Hickson, I just want

16:52:36 to thank you for

telling us your story, for sharing it,

16:52:40 for sharing a

part of Michael's story, and anyone

16:52:45 who has a heart

can only take that in and needs to sit

16:52:48 with it for a

moment.

16:52:51 And when I saw you talk -- tell your story, the

16:52:57 things that I saw on your face were little smiles and

16:53:02 what appeared to be glimpses of remembrance of someone

16:53:07 that you love, and not just love but still love and

16:53:13 that you hold in very high regard. And that the

16:53:16 events that have unfolded have probably -- have

16:53:20 changed you forever. And there is a term that I

16:53:23 recently came to learn about, which is called moral

16:53:30 injury. And moral injury is when we lose trust

16:53:34 because the thing that we believe are right and wrong

16:53:39 are turned upside down, twisted, zigzagy and it just

16:53:43 doesn't make anymore sense. And to your point, when

16:53:46 happens to us in our lives and in this moment, it

16:53:51 often leads to those feelings that you described where

16:53:54 people feel like I could have done more, I should have

16:53:56 done more. You feel bad that you didn't do all that

16:54:01 you could. But how can you do more when the world is

16:54:10 all SGLIGy SGLAGy turned upside down and doesn't make

16:54:14 sense. So the term moral injury really resonates to

16:54:17 me. Because you are correct. Those medical care

16:54:20 providers do take an oath. We take an oath of

16:54:25 nonmalfeasance to not do harm and to be good and to be

16:54:34 person centered, and that was not your experience. So

16:54:36 I just have to say that it's really amazing that

16:54:39 you're able to tell us the story, but I think it's

16:54:43 because of what you said that you want the story

16:54:47 heard. And we thank you for that. I guess I just

16:54:51 don't understand some things, and I just wanted to ask

16:54:54 just two questions. One was when the doctor referred

16:54:57 to the we who made this decision, who was he talking

16:55:04 about?

 >> MELISSA HICKSON: I can only

16:55:07 guess, because

I don't know exactly who he was

16:55:13 talking about, I, you

know, my thought was we was probably

16:55:19 the guardian that

was appointed.

16:55:22 >> ANN JACKSON: Okay. And how were they able

16:55:27 to change his code status in such a secretive way?

16:55:31 How could you not be notified when you reached the

16:55:34 guardian. Did the guardian know that they had changed

16:55:38 his code status? How was that done in the dark -- you

16:55:42 know, in the cloak of darkness in this way?

16:55:43 >> MELISSA HICKSON: Well, that's a very good

16:55:47 question. It probably is an Andres question, but I

16:55:49 don't know. Because they knew that under no

16:55:53 circumstances did I want him to be under DNR. They

16:55:57 knew. I think something that came across to me like

16:56:02 when they moved him to hospice, the hospice

16:56:04 representative did tell me -- actually the nurse told

16:56:08 me that well, it's impossible to be in hospice and not

16:56:12 be DNR. You can't be full code and hospice. So I'm

16:56:14 guessing that's the reason they changed it was because

16:56:17 when they moved him, they had to change it to DNR. I

16:56:21 mean, the two are conflicting if it's full code and

16:56:23 hospice, so --

 >> ANN JACKSON: And you did

16:56:26 not know about

this status -- I mean, you did not

16:56:32 know that to go to

hospice, you had to be a DNR? No one

16:56:35 had educated

you? No one had shared any of this

16:56:37 type of

information with you? You didn't

16:56:39 learn this until he

got there and then you had this

16:56:42 conversation?

 >> MELISSA HICKSON: So I

16:56:44 actually talked to

the representative from hospice. They

16:56:47 called me, and

she told me that you could be full

16:56:51 code in hospice.

And something just didn't seem right

16:56:53 to me about that.

But I wanted to confirm it with the

16:56:56 hospital. So I

called the hospital, and the nurse

16:56:59 said to me, no,

that's not true. You know -- and of

16:57:02 course when she

said it it clicked to me that that

16:57:06 does make sense.

You can't be both. So the hospice

16:57:09 representative told

me that you could be. But I didn't --

16:57:13 I had no clue.

 >> ANN JACKSON: Okay. Well, I

16:57:16 -- again, I'm

just going to thank you and I'm going

16:57:19 to pass it to

our fellow panelists because I know

16:57:22 they have

questions. But again, I acknowledge

16:57:26 you as a queen

and I acknowledge him as a king, and I

16:57:30 do recognize

and celebrate and honor your humanity.

16:57:33 And Michael's

as well.

16:57:36 >> MELISSA HICKSON: Thank you.

16:57:37 >> KRISTI KIRSCHNER: I'm going to turn now to

16:57:44 Dr. Lease a Lezzoni, who is a Professor at Harvard

16:57:52 medical school. But she also identifies as having had

16:57:57 multiple sclerosis for 44 years and a wheelchair user

16:58:04 since 1988. She's a health services researcher.

16:58:09 Dr. Iezzoni.

 >> Mrs. Hickson, thank you.

16:58:15 I'm afraid my

voice is going to be a little trembley

16:58:19 because I've

just been so profoundly affected by

16:58:25 what you said to

us. And cray Ti you anticipated that

16:58:29 I was going to

do this. I'm going to take a detour

16:58:32 to my Michael. I

have a dear friend who has progressive

16:58:35 MS and cannot

move any of his body below his neck.

16:58:38 And I'm his

health care proxy. And he lives 250

16:58:43 miles away from

me. But back in 2015, he started

16:58:49 developing a series

of symptoms that a first year medical

16:58:54 student could

have diagnosed as something that might

16:58:58 have been

malignant. And for six months, he's a

16:59:02 smart guy, he

wanted to advocate for himself. For

16:59:06 six months he

kept asking his providers to schedule

16:59:10 a

gastroenterology consultation, to

16:59:15 evaluate him. And

they said that they couldn't do that.

16:59:20 Finally I went

down to visit him for his birthday and

16:59:25 he -- his blood

pressure had gone up to 160 over 110.

16:59:27 It wasn't

controlled by medications. He could

16:59:30 only say about

three words before having to take a

16:59:34 breath. I had

been talking to him over the phone.

16:59:36 Again, he wanted

to continue advocating for himself.

16:59:39 And finally I

just looked at him and I said,

16:59:44 Michael, I've got an

M.D. after my name. I can talk

16:59:47 doctor. Would you

give me permission now to advocate for

16:59:52 you?

 And so I advocated for him with

16:59:56 his very

structured managed care health plan,

17:00:01 which was very --

they had gatekeepers everywhere. And

17:00:05 I insisted that

his primary care doctor get a CT scan

17:00:08 of his abdomen,

even though the primary care doctor

17:00:11 said no, it's

going to take us three weeks to

17:00:15 schedule it. Well, he

was able to do it within two days.

17:00:19 About a week

Michael was having a 15-pound tumor

17:00:25 removed from his

belly. This tumor had been sitting on

17:00:30 his femoral

veins, which is why his legs were so

17:00:38 swollen and it

had been sitting on his aorta, which

17:00:42 is why it -- it

had been pushing up on his diaphragm

17:00:45 which is why he

couldn't say more than two or three

17:00:48 WOSHDZ before

needing to take -- words before he

17:00:50 needed to take a

breath.

17:00:55 And when I talked to his doctors later on, when

17:00:59 he, Michael, came home, it was clear that they

17:01:02 thought, oh, no, his MS was just progressing. There

17:01:06 wasn't anything more that they could do for him. And

17:01:09 it was only when I talked to the social worker that

17:01:13 she said, oh, you know, our plan believes in

17:01:16 palliative care. We wanted to keep him comfortable.

17:01:22 We didn't want to do something that would make him

17:01:24 uncomfortable.

 I'm here to tell the medical

17:01:27 students who are

listening that palliative care does

17:01:31 not mean stopping

caring for people. It doesn't mean

17:01:39 not evaluating

them and seeing when there's something

17:01:42 that you can do

to save their life. So having that

17:01:47 15-pound tumor

removed, Michael is now -- it's 2021

17:01:51 and I will not go

into history weeks from hell with

17:01:54 COVID. I won't go

into that right now, but he did

17:02:00 survive, again, to

Mrs. Hickson, her husband Michael, my

17:02:03 friend Michael

was quadriplegic, couldn't move any

17:02:06 part of his body

from his neck down, obviously had

17:02:10 restricted pulmonary

status. He pulled through. And so

17:02:14 people, even with

significant disability can live from

17:02:19 COVID. But what

Kristi wants me here to do is to talk

17:02:23 in numbers,

okay? And so I'm going to step back

17:02:29 from the personal

to just give you some information that

17:02:32 can in an

empirical way, since that is what we

17:02:36 as scientists to,

we want to see what the evidence is,

17:02:41 I'm simply going

to validate what Mrs. Hickson

17:02:46 experienced and what her

doctor told her. So my colleagues and

17:02:50 I have

conducted the first ever national

17:02:54 survey of physicians

about their perceptions of and

17:02:56 experiences with caring

for people with disability.

17:03:00 We went into the field with a survey in October

17:03:03 of 2019. We actually didn't complete it until spring

17:03:08 of 2020 and COVID kind of intervened and are trying to

17:03:11 complete the survey. But we cannot assert that our

17:03:14 survey results say anything about COVID. They

17:03:20 basically are just COVID. But we asked questions --

17:03:23 we asked physicians a question about how they viewed

17:03:26 the quality of life of people with significant

17:03:30 disability compared to the quality of life of people

17:03:36 without disability. And 82 percent of doctors said

17:03:41 that the quality of life of people with significant

17:03:45 disability is worse than the quality of life with

17:03:50 people without disability.

 Now, for people who know

17:03:52 anything about surveys,

you know there's something called the

17:03:56 positive

response bias. That people respond to

17:03:59 surveys in the

way that they think society is going

17:04:00 to expect them to

respond.

17:04:04 And so you would have thought that a physician's

17:04:08 expected society to say that people with disability

17:04:10 have the same quality of life, which was one of our

17:04:13 options, that they would have said that. But, no,

17:04:17 what they said, 82 percent of them said was that

17:04:22 people with disabilities have worse quality of life.

17:04:26 What that is telling me as a researcher is that those

17:04:28 physicians don't think anybody's going to question

17:04:33 them. They think nobody is going to say that's wrong.

17:04:38 They truly believe that people with significant

17:04:43 disability have worse quality of life, that that is an

17:04:47 unquestioned thing.

 There were two other points

17:04:51 that I want to say

as high level responses to the survey.

17:04:54 And trust me,

I could go on for hours about other

17:04:56 responses, but I

won't do that. Just two other kind of

17:04:59 top line

responses from the survey.

17:05:03 Again, people like Andres are going to tell us

17:05:05 that the ADA requires people with disability to be

17:05:10 treated equitably as other people. And doctors are

17:05:14 nothing if they don't have self-confidence. Let's

17:05:16 just put it this way. Doctors are pretty certain that

17:05:23 they know what's right. But only 41 percent of the

17:05:29 doctors that we surveyed agreed or felt very confident

17:05:32 that they could provide the same quality of care to

17:05:37 people with disability as they do to other people.

17:05:42 That means nearly 60 percent of doctors do not feel

17:05:44 very confident that they can provide the same quality

17:05:47 of care to people with disability as they do to other

17:05:51 people, which is a pretty astonishing thing for

17:05:55 doctors to admit. The other thing is that only

17:06:00 slightly over half, 56 percent of physicians, strongly

17:06:03 welcome people with disability into their practice.

17:06:07 And so what that's saying is that almost half the

17:06:09 physicians to not strongly welcome people with

17:06:15 disability into their practice. So Kristi, is there

17:06:17 anything else more that you want me to say at this

17:06:20 point or have I kind of covered --

 >> KRISTI KIRSCHNER: I think

17:06:25 you've really

done a beautiful job, Lisa, hitting

17:06:29 the high points,

and it is data but it is very powerful

17:06:31 data, so thank

you. Thank you for sharing about your

17:06:35 experience with

Michael as well as the work you've

17:06:37 done. And I just

want to tell folks that there is no

17:06:43 one in the world

of medicine who's done more than Dr.

17:06:46 Lezzoni in my

opinion to change the landscape by

17:06:50 doing research.

 >> LISA LEZZONI: Well, Kristi

17:06:54 is saying too

much, and it's always a team effort.

17:06:58 Nobody can ever

do anything in life alone.

17:06:59 >> KRISTI KIRSCHNER: But it's true.

17:07:02

 >> LISA LEZZONI: Thank you.

17:07:05 >> KRISTI KIRSCHNER: So I'm going on to Dr.

17:07:08 Chicoine because I did think that we needed to hear

17:07:11 from a physician who cares for people with

17:07:16 disabilities, who can speak to the experience of his

17:07:20 work, caring for his patients during COVID.

17:07:25 So Dr. Chicoine is a medical director, the

17:07:28 advocate medical group, adult Down syndrome center.

17:07:33 And has served over 6,000 adult, adolescents and

17:07:36 adults since it opened in 1992. And I can tell you in

17:07:43 a very personal level that I have cherished meeting

17:07:50 Dr. Chicoine and seeing the values that animate his

17:07:53 life and his quality of care for his patients.

17:07:56 So thank you, Dr. Chicoine. Please share with

17:07:58 us your thoughts.

 >> BRIAN CHICOINE: Thank you,

17:08:02 Dr. Kirschner

and thank you, Miss Hickson for

17:08:04 sharing Michael's

story. I truly appreciated hearing

17:08:07 that. Earlier Dr.

Kirschner talked about crisis

17:08:11 standards of care and we

know there are national directives on

17:08:13 caring for

people with disabilities during the

17:08:15 pandemic.

However, despite those directives,

17:08:18 really so much of

the decision making is being made at

17:08:22 the bedside, as

Miss Hickson shared with us.

17:08:24 And I'd like to share a story of one of our

17:08:27 patients as well as a few additional thoughts. And I

17:08:29 will tell you that I did receive permission from the

17:08:32 individual's guardian to share this story. So to

17:08:34 better appreciate the story, it's good to understand

17:08:37 this occurred about ten months into the pandemic and

17:08:40 the hospital, I only had about a quarter of the COVID

17:08:44 patients that had been compared to the peak last

17:08:47 summer and spring. And there were both open medical

17:08:50 unit as well as intensive care unit beds at the time

17:08:53 of this story. And so this was a 60-year-old woman

17:08:57 with Down syndrome and early Alzheimer's disease was

17:09:01 admitted with COVID-19 pneumonia. I am her primary

17:09:04 care provider but also provide inpatient care when

17:09:07 hospitals are admitted into the hospital so I was part

17:09:09 of seeing her in the hospital as well. Prior to

17:09:12 becoming ill she was verbal, able to manage most of

17:09:18 her daily activities, ambulated and had a very sweet

17:09:20 disposition with none of the behavioral challenges

17:09:24 that are sometimes seen with people in down syndrome.

17:09:26 She had developed some memory impairment and required

17:09:31 some guidance with some of her daily tasks and lives

17:09:34 with her sister, her legal guardian. So upon

17:09:37 admission she was weak but interactive. She initially

17:09:40 required low amounts of oxygen. Was started on

17:09:45 recommends did he veer and was admitted to a unit. We

17:09:47 reviewed her (inaudible) with her family and the

17:09:49 framework of her total care and their sister requested

17:09:53 a full code.

 And the patient was no longer

17:09:56 able to understand

these issues or the demands DREK I

17:10:00 haves in the

discussion. . In the first 24 hours

17:10:04 unfortunately she

deteriorated, was transferred to the

17:10:10 ICU, and there

she required high flow but was not

17:10:13 intubated. Upon

admission to the ICU, very early

17:10:18 communication from

the intensivist was the question what

17:10:19 is her code

status. I explained the conversation

17:10:22 I had with her

sister and she requested that we

17:10:24 continue the full

code status.

17:10:26 For the first four of the six days that she was

17:10:29 in the ICU, I was asked the question again and again

17:10:33 about code status and the -- it became unclear to me

17:10:36 whether I was really being asked a question or I was

17:10:40 being told that she should be a DNR or have a status.

17:10:42 I discussed it again with her sister and again she

17:10:44 requested a full code status particularly early in the

17:10:47 course of her treatment as we were still seeing what

17:10:52 direction this was going to go.

 And these questions statements

17:10:55 actually

continued even as her oxygen needs

17:10:58 decreased. I did

grant that the providers in the ICU

17:11:00 had more

experience with treating COVID than I

17:11:02 did although

unfortunately I've had a fair amount

17:11:05 in the last year.

So on the fourth day I asked about

17:11:08 data or even

experienced the demonstrated the

17:11:11 medical futility of

what we were doing or might do if her

17:11:14 care needs

increased such as intubation.

17:11:16 There was apparently no data to be shared and

17:11:19 interestingly, I was not asked again about her DNR

17:11:21 status after I had asked that question.

17:11:24 In a few days she was transferred out of the ICU

17:11:28 in a week discharged home on room air, eating well,

17:11:31 ambulating and verbally interacting.

 Now, the advance track had

17:11:35 never specifically

came into her course as she was never

17:11:39 required

intubation or CPR certainly. But as

17:11:44 most physicians

know that one a DNR status is put on

17:11:47 the chart or

decided, it can affect treatment in

17:11:53 other ways,

whether subconsciously or consciously.

17:11:55

 So I asked myself are the

17:11:57 advance tracks of some

individuals with individual

17:12:01 disabilities quickly

changed to DNR when admitted for COVID

17:12:04 based factors

other than medical appropriateness as

17:12:06 seemed to be

what was driving the questions here.

17:12:09 And does the decision result in a different

17:12:12 level of care? Well, the different level of care

17:12:15 ultimately result in less successful treatment? And

17:12:18 will that become a sort of a self fulfilling situation

17:12:21 which providers give less care because they think

17:12:24 individuals won't do as well which leads individuals

17:12:27 not to do as well because we weren't giving them the

17:12:29 same level of care. So for individuals that don't do

17:12:32 well, what are the factors of risk that are intrinsic

17:12:34 to individuals. What are the genetic issues in the

17:12:37 case of people with Down syndrome but what are factors

17:12:39 related to needing care or assistance, particularly

17:12:42 when that care is insufficient as unfortunately

17:12:45 studies have shown that many people with intellectual

17:12:47 disabilities don't get day in and day out the care

17:12:50 they need and are there times when judgment or bias

17:12:53 results in less care that ultimately results in the

17:12:57 less -- or poor outcomes rather than really what's

17:13:01 intrinsic to the individual.

 There was a recent article by

17:13:05 Glee on titled the

devastating impact on individuals with

17:13:07 COVID-19 with

disabilities in the United States. It

17:13:09 was really

fascinating, 600 million patients

17:13:14 across 547 health

care organizations about 127,000

17:13:17 people with

disabilities were included in the

17:13:20 study and to compare

the groups with and without, they did

17:13:24 an adjusted odds

ratio and found individuals with an

17:13:26 intellectual

disability had a higher rate of

17:13:29 COVID-19 infection,

were more likely to be admitted to the

17:13:32 hospital with

COVID, were more likely to die from

17:13:35 COVID but did not

have a higher ICU admission rate. So

17:13:37 there was a

higher rate of infection, a higher

17:13:40 rate of admission

to the hospital, a higher rate of

17:13:43 death, but we were

not admitting them to the hospital at

17:13:47 the same higher

rate that we did as reflective in the

17:13:50 other factors

that were measured. So did decisions

17:13:53 about how much

care to provide ultimately contribute

17:13:56 to the higher

rate of death? Would the same

17:13:59 decisions be made with

the same characteristics in someone

17:14:02 without

intellectual disability? There are

17:14:05 over 200,000

people with Down syndrome in the

17:14:07 United States and

certainly more with many other

17:14:09 intellectual

disabilities. So these are not small

17:14:12 numbers of

individuals that these questions need

17:14:15 to be addressed.

A recent study found only 5 percent of

17:14:18 people with

Down syndrome have access to a center,

17:14:20 specifically

treating people with Down syndrome,

17:14:22 which would be

more familiar with co occurring

17:14:26 conditions, more

likely understand the breadth of Down

17:14:28 syndrome and are

perhaps more familiar with the

17:14:32 individual's daily

life. And certainly from Miss

17:14:33 Hickson's story, not

appreciating and understanding the

17:14:37 individual's daily

life is -- it really does lend one to

17:14:39 have a very

different skewed view of who the

17:14:42 individual is.

 So I -- again, I think, you

17:14:46 know, one of the

things I think is -- that Dr.

17:14:49 Kirschner asked what's

the advantage of having a care at a

17:14:53 center for Down

syndrome. You know, I think -- I

17:14:56 think honestly the

biggest thing is appreciate our

17:14:59 patients as

individuals with intrinsic value is

17:15:01 the number one

thing but certainly the ability to

17:15:04 understand what

their health conditions are is a huge

17:15:09 piece. And it

was so interesting to read Dr.

17:15:14 Lezzoni's paper, recent

paper. And if people with interselect

17:15:18 UL disabilities

do have a lower quality of life,

17:15:20 really is it because

of their personal qualities or is it

17:15:23 because of our

society's approach to them as people?

17:15:25 And I would

certainly argue that it's much more

17:15:27 the latter and not

the former.

17:15:31 Just one other comment. I do want to make is

17:15:35 that I'm not suggest THAG we want to deny palliative

17:15:37 care and hospice whenever appropriate for individuals

17:15:40 with intellectual disabilities. There are times when

17:15:43 that's appropriate. Unfortunately people with Down

17:15:46 syndrome develop more Alzheimer's disease and we

17:15:49 certainly admit people with end stage Alzheimer's

17:15:53 disease where a discussion is had with the family or

17:15:57 guardian and we decide to provide hospice care.

17:16:00 So I'm certainly not suggesting that it's always

17:16:04 incorrect. But certainly I think we do really -- as

17:16:07 Miss Hickson really pointed out, you really have to

17:16:09 have honest conversations with people and sort this

17:16:13 through and sort out what -- what are the wishes, who

17:16:16 is the individual and how would we -- what would be

17:16:19 the decision to best treat this individual.

17:16:21

 >> KRISTI KIRSCHNER: Thank

17:16:26 you. I have to say

there is a nugget here that I want to

17:16:32 shine a light on

in terms of best practices and maybe

17:16:37 some promising

solutions because the advocacy of a

17:16:41 primary care

doctor who knows his patients

17:16:45 understands them as

whole people, understands their

17:16:50 disability can make a

huge difference in a scenario like

17:16:52 this where we know

a lot of health professionals TOENT

17:16:55 have that -- don't

have that depth of knowledge and

17:16:59 training. So the

advocacy that Dr. Chicoine does by

17:17:03 just showing up and

being a part of the conversation is

17:17:07 huge.

 So we are at 5:17. We've got

17:17:11 13 minutes left.

And I want to first tell Mrs. Hickson

17:17:15 that there are a

lot of comments in the Q and A

17:17:23 thanking you and

expressing condolences and comments

17:17:25 about the

importance of the story and how can we

17:17:29 use this to

become a transformative experience in

17:17:31 health care and

whatnot.

17:17:34 Please know that we will capture those for you.

17:17:38 We won't have a chance to say all of this today.

17:17:44 We do want to take just a moment here to turn to

17:17:51 jam board and share with our audience how we would

17:17:54 like to encourage you to engage if we can't get to

17:18:00 questions of everyone.

 I'd like to introduce Miss Gaby

17:18:04 Pena who is

helping us moderate the jam board to

17:18:07 just do a quick

tutorial. She identifies as a

17:18:12 daughter, sister, aunt,

survivor of invisible chronic

17:18:17 illnesses and a champion

of social justice and public health.

17:18:20 So Gaby, why don't you just say a few words

17:18:24 about how people can also go on the jam board to share

17:18:27 their stories, comments, and thoughts.

17:18:30 >> GABY PENA: Absolutely. Thank you so much,

17:18:33 Kristi, for that introduction. As Kristi mentioned, I

17:18:35 would like to welcome everyone to please make use of

17:18:40 our jam board, to go ahead and share your comments,

17:18:44 reactions, and questions to today's session but also

17:18:49 to our previous sessions if you have not been able to

17:18:53 join us during the live sessions. We do also have

17:18:59 those made available online.

 If I may please have the

17:19:06 ability to share my

screen, I would love to just -- thank

17:19:14 you so much.

 So I would first like to just

17:19:19 make reference to

the website that has been made

17:19:24 available for this

seminar series. If you were to scroll

17:19:28 down on our

landing page, you will notice that

17:19:35 there is a join the

discussion tile which provides both a

17:19:40 PDF guide on how

to use jam board. I don't have time

17:19:43 to go through

this entire guide, but I do just want

17:19:48 to hit on a few

major points. And that is

17:19:57 accessibility. So that's

been one of the themes and

17:19:59 underpinnings of the

seminar series. I just want you to

17:20:03 know that jam

board can be used on Macs, PCs and

17:20:06 mobile devices. If

you do choose to use a mobile device,

17:20:09 just know that

editing tools may not be on the left

17:20:12 pane as is the

case if you are accessing jam board on

17:20:15 a personal

computer.

17:20:18 Additionally, jam board does allow for real time

17:20:24 editing. So please don't worry about your content and

17:20:28 additions being saved if you accidentally click out

17:20:32 of -- out of the tab, don't worry. It will be saved.

17:20:37 So again, this resource is made available on the

17:20:42 website, and it's underlined and hyperlinked on this

17:20:48 brief presentation. Additionally, if you click on

17:20:50 share your voice on jam board, it will go ahead and

17:20:55 send you over to our jam board. Again, if you were

17:21:01 not able to attend the live seminar series for

17:21:07 sessions one and two, please feel free to again on our

17:21:10 landing page, feel free to view the session

17:21:14 recordings, and you are more than welcome to add your

17:21:18 respective questions and comments to those sessions

17:21:21 regardless and whether or not you were there for the

17:21:26 live session. And just be sure that when you are

17:21:29 adding your respective questions, comments, and

17:21:35 reactions, that you just take note of which session

17:21:40 you are going to be adding your comments to. So for

17:21:43 example, today's session, session 3, I'm covering

17:21:47 disability bias and discrimination health care. You

17:21:52 would go ahead and add your feedback on this frame.

17:21:57 Additionally, there is an additional questions

17:22:04 frame. So if you have any questions that have -- if

17:22:07 space is an issue on any of the other frames, please

17:22:09 feel free to add your comments on the slide.

17:22:13 Do take note that if you are going to add, if

17:22:16 you can select any color on the sticky note, other

17:22:21 than green, those of us on the panel and the steering

17:22:24 committee will be answering your questions using a

17:22:28 green sticky note. But do feel free to add your

17:22:32 comments on -- with any other color.

 Additionally, if you have any

17:22:36 questions about

jam board, please feel free to email

17:22:41 me. I will add

my email in the chat and I will be

17:22:45 more than happy to

assist you. Thank you.

17:22:47 >> KRISTI KIRSCHNER: Thank you, Gaby. So I

17:22:49 hope that you will take advantage of this. I can

17:22:52 guarantee you we have lots and lots of topics and

17:22:55 issues that we have not unpacked and we're not going

17:22:58 to have time to. But hearing from you will help us

17:23:01 think about future sessions. It will also give us an

17:23:04 opportunity to address questions that you have from

17:23:10 this particular session.

 I do want to thank the people

17:23:16 who are moderating

the Q and A and invite Dr. Pringl

17:23:23 Miller to also make

some comments. We have -- Dr. Pringl

17:23:27 Miller who's a

surgeon as well as a specialist in

17:23:32 palliative care and

hospice and an ethicist. She also

17:23:36 fears advocate for

equity and my nor advertised and

17:23:38 marginalized health

care providers and patients and in

17:23:41 particular, I've

invited her to help us parse the

17:23:44 difference between

palliative care and hospice but also

17:23:54 to comment on

other issues that she'd like.

17:23:55 >> PRINGL MILLER: Thank you, Kristi. This has

17:24:03 been a remarkable discussion and I echo Lisa Lezzoni.

17:24:06 And I want to say thank you to Mrs. Hickson for

17:24:08 sharing and you and Michael deserve so much better

17:24:11 from our health care system and I'm so sorry on behalf

17:24:16 of my colleagues in medicine. I am as Kristi said, a

17:24:21 hospice and palliative medicine physician, and it --

17:24:25 the experience you had mirrors others who really have

17:24:28 a bad taste in their mouth about what hospice and

17:24:31 palliative medicine can offer people in our

17:24:37 communities. So to clarify, I have worked in

17:24:40 in-patient hospice units in the city of Chicago and we

17:24:44 have never had a policy within the company that I

17:24:48 worked in that a patient needed to be DNR in order to

17:24:53 be admitted to our hospice or to enroll in hospice.

17:24:56 Hospice is a Medicare benefit, as people may know, and

17:24:59 there isn't an inclusive criteria that requires that

17:25:03 somebody have a DNR order to avail themselves of that

17:25:07 benefit.

 Having said that, the basic

17:25:10 premise of hospice

and palliative medicine and the

17:25:15 distinction being that

palliative medicine is for any patient

17:25:18 who is

suffering with symptoms with serious

17:25:21 illness whereas

hospice is specifically for those

17:25:23 people who are at

the last six months of their life to

17:25:27 the best of our

ability to predict that. And as you

17:25:29 pointed out in

your story, we don't always know

17:25:33 everything. And we

can't always predict everything. And

17:25:36 it should be

very transparent that that's the case

17:25:41 when it is the

case.

17:25:44 So we in hospice and palliative medicine are

17:25:49 very focused on patient con cordant care plans meaning

17:25:52 we are very much interested in knowing the narratives

17:25:54 and the preferences and the goals and the values of

17:25:57 the patients that we're taking care of. And that is

17:26:00 really the infrastructure that helps us determine what

17:26:07 the care plans are for patients.

 So unfortunately a lot of those

17:26:11 principles were

violated in Michael's case and hospice

17:26:14 and palliative

medicine, we not only take care of the

17:26:16 patient but we

take care of their caregivers and

17:26:18 their community.

And your rights were very much

17:26:24 violated as well. So I

hope that clears up some of the

17:26:30 comments that were

stated earlier.

17:26:32 >> KRISTI KIRSCHNER: Thank you, Dr. Miller.

17:26:36 That's very helpful. I also want to call out Eric

17:26:39 Swirsky who's been helping us moderate the chat in our

17:26:43 prior sessions as well as today. He prefers to be

17:26:47 identified simply as a human. And so I think that

17:26:51 must resonate Miss Hickson, with what you're saying.

17:26:54 We are humans and we need to listen and we need to

17:26:57 connect with each other.

 So thank you.

17:27:00 We have one question in chat that I would like

17:27:05 to close with. And I'm going to ask Dr. Jackson maybe

17:27:12 to field it. I'd like to invite other people to

17:27:15 comment. But before I do -- so I'm not going to pull

17:27:18 back, share a screen at this point. I don't want to

17:27:22 take that time. But we do have a survey that we hope

17:27:25 you will fill out. It will be coming in the next day

17:27:29 or two. We very much want this to be a conversation,

17:27:32 your responses and your suggestions matter to us

17:27:34 deeply.

 And we're beginning to think

17:27:37 about next steps.

 The session for next week,

17:27:40 we're going to pull

in a lot of what we've heard from the

17:27:44 community and

themes that we've heard from our

17:27:47 panelists and talk

about transformation. How do you take

17:27:51 this moment in

time, take what we've heard, and go

17:27:54 forward.

 So please do the survey,

17:27:59 provide comments on jam

board. And the question that came

17:28:06 into the Q and A is

really about intersectionality with

17:28:09 race and

disability. So let me open it up to

17:28:12 Dr. Jackson and

if anyone else would like to comment,

17:28:18 we'll close with

that.

17:28:19 >> ANN JACKSON: I think that's been a burning

17:28:23 question on my mind as well, as we heard the

17:28:27 conversation. And I think the times that we find

17:28:30 ourselves in, especially today and what's happening

17:28:34 around our country, you have to wonder about that.

17:28:38 And I think that in last week's conversation, we

17:28:41 talked about intersectionality and that certainly some

17:28:44 things do exist in parallel but some things actually

17:28:48 cross and intersect. And I think that I have to

17:28:54 wonder not only about the impact of the Hickson

17:28:58 family's -- or Michael Hickson's disability but the

17:29:03 Hickson family's race and how did that play into the

17:29:07 views of this physician.

 And I -- I don't know the

17:29:12 answer. Perhaps my

colleagues can offer something. But I

17:29:16 do think we

would be remiss if we did not bring it

17:29:20 up, especially

as we think about equity and ethics.

17:29:24 And as Dr. --

well, as the panel has just talked

17:29:28 about disability,

and I just wonder, you know, how does

17:29:33 disability and

race, and perhaps even gender

17:29:39 identification, how do

those other identifiers intersect to

17:29:43 minimize or

complicate or distract from or

17:29:47 minimize the care that

one gives -- is given. So I

17:29:52 appreciate the question.

And I do think it has to be a part of

17:29:55 this

conversation.

17:30:03 >> KRISTI KIRSCHNER: Thank you. Anyone else?

17:30:08 Well, I think we will bring this to a close then --

17:30:12 >> Wait, Lisa has a comment, I think.

17:30:13 >> KRISTI KIRSCHNER: I'm sorry, Lisa.

17:30:15 >> LISA LEZZONI: I'm sorry, Kristi. In my

17:30:19 early work on disability I focused on disability

17:30:22 invisibilityment and one thing that I heard from Black

17:30:25 participants who I would interview is that they would

17:30:29 come in to an emergency department, for example, with

17:30:33 impaired gait. You know, they'd be maybe broad based

17:30:36 gate because they had multiple sclerosis or something

17:30:38 like that. And the emergency department physicians

17:30:42 would always say, oh, you must be drunk. You must be

17:30:45 high on drugs. That's why you're having trouble

17:30:48 walking. So there was just always for them, from

17:30:52 their perceptions, their experiences, was that the

17:30:55 initial assumption was not that they had something

17:30:59 medically going on but that they had substance abuse,

17:31:03 they were out, you know, abusing alcohol. And so it

17:31:10 was just -- it just sets up the clinical encounter to

17:31:15 be one of disrespect and it can really compromise

17:31:21 health care for those patients. That's my comment.

17:31:23 >> KRISTI KIRSCHNER: Yeah, very powerful and

17:31:25 we've certainly seen that in chronic pain, you know,

17:31:28 when people come into emergency rooms and care

17:31:31 settings, that there are racial differences in how

17:31:33 people are treated.

 Very important issues that

17:31:37 we're touching on.

And like I say, this is just touching

17:31:40 the surface.

But this is why we want to do this.

17:31:42 These

conversations are extraordinarily

17:31:46 important. And,

yes, they have to be contextualized in

17:31:49 the story, in

the human story, in the experience of

17:31:53 individuals who

are the heart and soul of health care.

17:31:56

 So thank you from the bottom of

17:32:01 our heart, Mrs.

Hickson, because we know it's not easy

17:32:04 to do and we

also know you're coming up on the

17:32:11 anniversary of his

death. And we all hold you in our

17:32:13 thoughts. So thank

you.

17:32:18 And Andres, thank you for facilitating this

17:32:23 powerful conversation and the work you do as a

17:32:29 disability rights lawyer and for Dr. Jackson, Dr.