

11:09:08 >> TEDRA JACKSON: Good morning, everyone, and welcome to our 8th informational webinar. And today we're talking about knowing your rights when it comes to medical treatment.

11:09:19 This is for COVID-19 and beyond. Our presenter is Jan Lampman and Mary Shehan-Boogaard. Without further adieu. I will turn it over to Jan.

11:09:34 As always, sorry, Jan. We do have closed captioning and if you would like to enable the closed caption please click on the up arrow to the right of the CC button and click on show subtitles.

11:09:49 Also, we will take questions or comments in the chat box if you don't want to ask your question or make your comment aloud, we will be monitoring the chat as well as grabbing comments from Facebook.

11:09:51 From our Facebook live.

11:10:01 And so now, Jan, now that we've done all of our housekeeping. Again, I want to apologize and thank everyone for joining us today.

11:10:03 We will go ahead and get started.

11:10:06 >> : Thank you so much, Tedra.

11:10:16 Thank you for asking Mary and I to talk about this important topic. I want to give a little context how the presentation came about to start with.

11:10:30 And that is that when people were first really getting sick with COVID-19 and were entering hospital and all of the worry about hospitals becoming overburdened they were some.

11:10:57 Actually, I think they were providers, service providers that were sharing stories about how like at a group home, the whole group home all of the guardians were asked to sign do not resist at a time of -- -- was getting the medical care they needed.

11:11:19 And a lot of talk about the medical supplies and hospital beds during the beginning of this pandemic. And then some self-advocacy advocates felt we always get discriminated when trying to get medical care and treatment.

11:11:20 It's not new.

11:11:27 So this, as Tedra said, we put together this presentation to help people what their rights are.

11:11:42 Not just during this pandemic and crisis and beyond, because we're going to talk about the ways you had before COVID-19 and rights that you had during this pandemic and rights you will have.

11:11:45 That is just a little bit of the context.

11:14:12 That the basis for these rights that we're going to talk about might come from a couple of different laws. One of them being a federal law the Americans Disability Acts and in Michigan the Civil Rights Act. Everything we're talking about is based on existing laws. -however, what we knew in the early days of the pandemic.

11:14:27 Is on the call. Kyle has joined our call and at one point give us an update what he and other advocates are going to make sure our rights are protected.

11:14:30 >> : HI, Kyle.

11:14:46 >> : At the beginning of the pandemic. We were seeing evidence that people weren't following the American Disability Act or maybe hospitals didn't understand.

11:15:03 So there were some actions that Kyle and other advocates took.

11:15:05 >> TEDRA JACKSON: The slides are not ready.

11:15:07 >> : That is okay.

11:15:12 >> : Okay.

11:15:13 >> : There we go.

11:15:14 >> : All right.

11:15:17 So if you want to go to the first one, Tedra.

11:15:20 >> : We can talk about what we have a right to.

11:15:22 >> : These are rights.

11:15:25 >> : That you have, that everybody has.

11:15:38 >> : We all have the right to equal access to health care. That means that we have the right to go to the emergency room or go to a doctor or get a doctor's appointment, just like everybody else.

11:15:39 Pretty simple.

11:15:54 We have the right to equal treatment option as well as people with disabilities. One of the things we were hearing happening sometimes is that people who had, what they were referring to as preexisting conditions, right.

11:16:11 People who might have a disability or some kind of health concern were potentially not going to be based on some rationing come types of criteria and not given the same options as other people.

11:16:28 Before COVID-19 I can remember times going with folks that I was supporting doctors and doctorses not understanding they had an equal right had a Colonoscopy if they were over 50.

11:16:35 It's important to know you have the right to equal treatment option. If I have that option you have the option.

11:16:38 You also have the right to tell doctors how you want to be treated.

11:16:46 You have the right to decide if you want to sign a do not resuscitate order or not.

11:17:00 There shouldn't be an assumption that somebody else is going to decide for you. Especially for people who have developmental disabilities. There is this assumptions they aren't going to be a part of the decision making process.

11:17:03 Okay.

11:17:18 You also have the right to have a patient advocate or someone to help to make decisions to be able to speak to them and even in this time of COVID-19 have the person at bedside if you need them.

11:17:41 There was just a decision, make you're going to talk about this Kyle, and came out of the east coast Massachusetts, or KRI Connecticut where a lawsuit filed related to person who had a communication disability not being able to have their family at bedside to help communicate with them.

11:17:56 And so the court ruled that, yes, you absolutely, just like the American Disabilities Act said you have the right to have someone at bedside to help you with communication or decision making if that is what you need.

11:18:06 Also, because of DWOEKS advocacy and a waiver that the Michigan wrote you have the right to have direct care workers.

11:18:19 Let's say you have somebody who needs help with eating and other daily activities and you have community living support. Okay, what happened here.

11:18:22 So and you need community living support.

11:18:40 You have the right to have that care work er with you at bedside and in fact right now, the way that our waiver has been, the way our waiver has been tweak for the COVID-19 crisis direct support profession al can be paid.

11:18:45 You also can be have your service dog with you if that is what you need.

11:18:47 Next slide.

11:18:52 You have all of these rights. You had them before COVID-19. You have them now.

11:18:57 Can we go to the next slide.

11:18:58 There we go.

11:19:07 So one of the things that with regard to decision make ing that we want ed to point out and Mary is going to talk a whole lot more about this.

11:19:37 It's really important that if you do, whether you do or don't. I had this conversation with my son. I think it's really important to anybody that might be help ing us to make medical decisions before we need to make the med DIGS and unable to speak for yourselves in the hospital. And need to know what your current medical needs and treatments you do or do not want.

11:19:54 When would you want CPR and a situation you wouldn't want CPR. So having those conversations with the people in your life before you get sick or before you need to have their assistant with health care is really, really, important.

11:19:56 Okay. Next slide.

11:20:01 >> : There we go.

11:20:10 >> : So one of the things that we were hear ing that was sort of happening and we want to make sure you understand. These are things hospitals cannot do.

11:20:14 Cannot refuse to treat you because you have a disability.

11:20:23 That was one of the things that people were somewhat afraid of this whole idea hospitals would become overly fill ed.

11:20:31 They are not to place people with disabilities on a LOU er priority for treatment because of their disability.

11:20:38 I saw somebody in the chat said, maybe made a comment that might, that is not always been our experience.

11:20:43 Sometimes people with disabilities are place ed on a lower priority for treatment.

11:20:50 And that was the fear now, during COVID-19, but I think a reality even before.

11:21:05 I know that I help ed a lady one time on a organ transplant list and fight for her to be on the organ transplant list because of the nature of her disability.

11:21:13 Was able to get on it and did get her kidney.

11:21:23 They can't discriminate against you for having a disability, your race, gender, your health status, your sexual orientation or identity.

11:21:26 Those are all things hospitals can't do.

11:21:28 Whether there is a pandemic or not.

11:21:37 So can you go to the next slide.

11:22:06 So now, this slide is talk ing about steps to support a decision make ing which Mary is going to talk about. I like to ask Kyle to unmute. Kyle Williams is from Michigan Advocacy and like him to share to make sure all of these rights I just talk ed about are actually being honor ed in the state of Michigan.

11:22:23 >> : So Jan asked me to come over and share with you some of the advocacy efforts that we've been doing and other organizations with regard to the COVID and address ing some of the issues and became apparent.

11:22:34 Probably best to know a lot of the issues aren't new issues and COVID exacerbate ed a lot of the previous problems with our system and health care system in particular.

11:22:43 Some of the efforts that we went through primarily reVOL V ed around COVID. They are not new.

11:23:10 Probably the majority of our efforts gone into an issue call ed medical ration ing. In lame term when ever there is not enough medical resources available for the amount of need for medical resource and the result is that medical ration ing health care system are make ing decision who gets care and does not base ed off limiting resources.

11:23:17 That is extreme ly concern ing for us. People with disabilities get at the bottom of the priority.

11:23:19 For medical resource priority.

11:24:23 And that is a number of reasons, but we original ly reach ed out to the legal affairs department on behalf of my organization the ACLU as well as attorney and law professor Sam, and present ed some guide ing principles that we would expect the state to implement with regards to medical ration ing and all of those principles stem from the general assumption all life has worth include ing people with disability and your life is worth save ing.

11:24:42 And we were able to get some movement from the federal OCTR and came out with a statement band ing certain principles be aapply ed to medical ration ing and provide ed a better support on our legal basis.

11:24:51 And what we chose to do is form a broad coalition of disability rights advocacy. I'm blank ing on the exact number.

11:24:59 I want to say, include ing attorneys that practice in the area as well as groups and individual folks that work in industry.

11:25:13 We had about 15 to 20 folks that sign ed onto a letter, detail ing what we felt like the issues with medical ration ing and asking the state to take some action.

11:25:44 What the letter end ed up result ing an executive order 2024. And that order pertains to folks rights to health care and that is specifically -- not limited to folks with disabilities and folks with protect ive classes, but does have some strong protection with folks with disabilities in the event there would be ration ing and general speak ing what the rights are to health care in general.

11:25:56 The highlights of that had a firm statement that medical treatment will not be base ed on stereotype, quality of life, assessment, or judgment about an individual's worth.

11:26:24 So those are really key aspects that we want ed to get address, because oftentimes a diagnose or a type of disability carries with it stereotype to the health care provide er and use ed against you negatively. And what the key aspect make ing a decision in medical ration ing is not what your diagnoses or quality of life if you were to get out of the hospital.

11:26:38 Whether or not you can benefit from treatment or whether or not what we determine long TIERM. Term.

11:26:59 That that cancer diagnosis solely is not going to deprioritize you automatically. They would have an individual assessment based off your medical evidence to make a determination rather than just deprioritize based off of your diagnosis of your disability.

11:27:09 We got strong support out of the executive order with regards to health care and providing support for functional needs in the health care.

11:27:40 That is a lot of what Jan is talking about with your ability to get supports if you need help to help you eat, take care of you or non-verbal or had trouble recounting your medical history and have support in the hospital and be able to maintain your daily needs in addition to whatever else is going on with you. So we got really good language and protection on that out of the executive order.

11:27:54 And we got guarantee, for ASL interpreters if that would be an issue and have sign language interpreters and speak with their doctors. And got firm statements with regards to.

11:28:00 You know, the need to accommodate that in a hospital setting regardless of COVID or otherwise.

11:28:27 And probably the key determination to take out of the executive order, they made an order that clinical decision making must be based on the best objective medical evidence that includes an individual assessment. That language takes it away you have X disability or preexisting conditions or prioritize or getting a ventilator or whatever it is that may be limited.

11:28:53 And takes it over to the individualize assessment using that medical data that is available in order to make a determination on what your long term survivabilities is. Those are key aspects addressing potential discriminate and we got solid support from our governor on that executive order.

11:29:01 After that we had some outstanding request what we were looking to do.

11:29:23 One of the things we want to do is compile and track data on people with disabilities. Right now anybody that is following the issue we have rapidly available information where the COVID outbreak is happening and on racial minorities and published as well as the total number of death verses cases.

11:29:54 So we want to the state to compile and track a report that data on COVID on people's with disabilities in a similar way they would do with folks in minority population that have the effective ness virus and track and shown and primarily on the African American community and Hispanic and other minority groups and disproportionate impact on that.

11:30:37 Continuing to work with the state on and trying to get some specific fixes with our ventilator relocation policy, but ultimately we have seen the numbers trend downwards. Continue to trend downwards and my anticipation our curve flatten in Michigan and we're trying to encourage them to take some action on that, but you know, regardless they know what our concerns are and relatively fixing and hopeful to make some more movement on that as well as issues on policies.

11:30:41 And again, the data collection that we're urging the state.

11:31:03 So in addition to medical rationing we addressed problem with services with regard to COVID. Whenever COVID happened stay away from everybody and use PPE. And we're progressing as a society to become more and more integrated.

11:31:38 Very early on tremendous concerns that folks that receive services in our community are not going to have those and ultimately those services are required for them to stay in the community and stay out institution setting, group home, or hospital or otherwise. We took action to ensure that that the state was going to provide guidance and require before COVID and afterwards.

11:32:04 Work with the department and issue guidance documents and prepatient and as well as community mental health and aging and with regard to telehealth and what services you could go not.

11:32:08 >> : Within the service you could provide ADA services.

11:32:15 >> : ABA services. The notion that you could provide that over the phone is somewhat complex.

11:32:41 So we sought the department and able to get some guidance how to provide telehealth services and as well as when you cannot do that to set up the procedure and receive those face to face. Somebody that needs help to get out of bed and cooking a meal and somebody that needs the hands on care you can't do it over the telephone.

11:32:51 We want to make sure, simply because they needed to be provided with face to face.

11:32:57 We felt people were entitled and state and give some guidance.

11:33:31 And behavior health services is essential. That was important. Whenever the governor came out with the executive order and limited in COVID and services and what was deemed essential services. Broadly define as health care services unclear community mental health or some of the other things long term care or physical health care services.

11:33:59 We were able to get some additional guidance to the people in the community mental health to establish the services are essential and provide the basis they would be in compliance with that executive order in order to provide that service, because some CMH did have a concern sending people into the home because of COVID.

11:34:40 And pre -- try to -- -- under the general notion that the last place you want to be right now is in a nursing home. It's an institutional setting. This is where we have seen problems in the state and nationally with regard to the COVID outbreak and every disability rights organization in the state to ensure we're going to get continue robust services in order to keep the folks in the community.

11:34:49 Where we felt they were the most safe and least at risk contracting COVID.

11:35:05 And we got some lighter language within the guidance to encourage CMH to not terminate residents. That is straightforward. If you had a medical need before COVID. COVID didn't change anything.

11:35:26 If anything COVID made it worse. CMH would reduce your services in light of COVID was something we found extremely problematic. And get some guidance out. It provided additional supports.

11:36:08 That is kind of brief run down of the two major issues we were able to deal with and have success with regard to the outcomes. There is still a lot of things on the horizon to be worked on and had that on the with protection and as well as organization center for public representation out in New Hampshire. And brought a complaint to hospital visit and overly restricted for an individual that was done verbal.

11:36:24 Where it's kind of create ed a problem of recount ing medical history and as well as center medical treatment. So that person need ed a patient advocate and had the access restrict ed to them.

11:36:37 Not only did OCR agree that restrict ed access was inappropriate and state issue a reorder on hospital policy.

11:37:01 With that add ed support we're in a better position try ing to approach the state out of the having to pay individual or to court that were necessary in order to enforce those rights. You're asking for a accommodation from a no visit as a result of your disability. Due to the disability you would need the patient advocate in order to recount your medical history.

11:37:06 So you know it's a very simple straightforward.

11:37:09 >> : That we can make some progress on that.

11:37:10 >> : Sorry.

11:37:13 >> : Some kind of background sound.

11:37:16 >> : I think someone needs to mute themselves.

11:37:19 >> : I hear a child.

11:37:21 >> : Okay.

11:37:22 >> : Okay.

11:37:24 >> : There we go.

11:37:45 >> : So Kyle. That talk ing about that visit policy brings us back around to the fact that people have the right to have the person at bed site for whatever need. Help eat ing or if they need help hear ing what the doctor said and make ing decision, right?

11:37:46 >> : Right.

11:37:55 >> : I think that is a kind of a good way to segue into Mary to talk to us about what kind of support we can have.

11:37:59 >> : When we need support with make ing decision.

11:38:08 >> : Who is the person at bed site? Mom? Sister? Guardian? One from your circle, right?

11:38:14 >> : Mary, are you ready to sort of share with us some of the ways that people can get that support.

11:38:15 >> : I am.

11:38:22 >> : And so I think what would be best to do here. I'm going to stop share ing my screen for a moment.

11:38:25 >> : I saw a lot of clicks on the chat box.

11:38:30 >> : So I'm presume ing that people have some questions for you and Kyle.

11:38:35 >> : And go through and give them an opportunity to answer that and then I will move on from there.

11:38:41 >> : I'm going to stop .

11:38:53 >> : People have just been say ing good morning. And a couple of resources and make it into the website underneath the record ing. Will be the presentation and the executive order.

11:38:55 >> : Okay.

11:38:56 >> : I just.

11:39:03 >> MARY SHEHAN-BOOGAARD: And I want ed to make sure that the questions got answered if there were any.

11:39:03 >> : Hello.

11:39:06 >> : I have a question.  
11:39:08 >> : For Jan.  
11:39:12 >> : What is your background?  
11:39:14 >> : What is my background?  
11:39:19 >> : Okay. So 35 years I was a direct support professional.  
11:39:36 >> : And then I became an advocate and work for the The Arc before I retire it had. I'm a mom of a son who has autism. Going to be 20 years old in a couple of weeks.  
11:39:46 And I've been working try to advocate for people's Civil Rights for my whole adult life.  
11:39:47 >> : Thank you.  
11:39:49 >> : Yup.  
11:39:53 >> : Hello.  
11:39:57 >> TEDRA JACKSON: Before we move onto Mary are there any other questions?  
11:39:59 >> : Yes, can you hear me.  
11:40:10 >> : Okay. I saw someone in the chat box said they had a client who couldn't get tested because she used a wheelchair and that is crazy.  
11:40:35 >> : That should not be an impediment if anyone listening had some guidance. I don't know if they are indeed in Michigan. Some areas mobile testing is set up and there has got to be a way for this person get testing. Wheelchair should not be an impediment.  
11:40:38 >> : I would like to hear from that person.  
11:40:41 >> : My name is Sue.  
11:40:48 >> : And the reason I made that comment was because they don't have transportation.  
11:41:01 >> : And transportation was stopped. So there was no way she could get to a testing site. But (audio is cutting in and out).  
11:41:26 >> : And not everyone has a way. She takes public transportation, but there wasn't available to her to go to a testing site. Had a wheelchair ramp.  
11:41:33 (Audio is cutting in and out).  
11:41:36 >> : Transfer to to the car seat.  
11:41:47 So I just wanted to put that in there, you know, just make you guys aware of that. That was one thing that we faced.  
11:41:57 And fortunately she did get better. She still wanted to go physically.  
11:42:17 >> TEDRA JACKSON: I'm going to see if, someone is on the line and if any of the new testing sites that are coming up would be.  
11:42:28 Any implications, Angela, is saying individual has Medicaid testing would fall with the eligibility of medical transportation.  
11:42:30 >> : That is correct.  
11:42:42 >> : She should have been able to be transported to a testing site and covered under Medicaid.  
11:42:50 >> : Yes. So, (audio is cutting in and out).  
11:43:01 >> : Tried to call (audio is not coming in clearly).  
11:43:08 >> : Was only one we had to actually transition into the car.

11:43:19 >> : Did not have transportation for wheelchair lift. And we call ed three different companies.

11:43:30 >> TEDRA JACKSON: Your audio, it drops and kind of split ing and so, I don't know if you have.

11:43:33 >> : Okay.

11:43:36 >> : Maybe.

11:43:45 >> : Kyle, and Jan, if you have contact information maybe this individual could contact you direct ly.

11:43:47 >> : Follow ing the presentation.

11:43:51 >> : To be able to get some more information on that.

11:43:54 >> : I can leave my contact in the chat.

11:43:59 >> : I can't hear a word of that. It's not come ing in clear for me.

11:44:02 >> TEDRA JACKSON: Go ahead and put your information in the chat.

11:44:06 >> : Okay. Great.

11:44:11 >> MARY SHEHAN-BOOGAARD: I'm going to go back to share ing my screen.

11:44:25 >> : Okay. So one of the reasons we want ed to infuse ed support ed decision make ing conversation into this presentation is that medical issues are one of the main reasons.

11:44:31 Why people that people give for petition ing for guardianship for someone.

11:44:40 It's often heard that they are unable to make medical decisions so they're going to need somebody to make that decision for them.

11:44:53 With support ed decision make ing there is a lot of tools that can help an individual prepare for medical procedures that they might need and plan for that ahead of time.

11:44:57 So again, people can communicate through their voice.

11:45:04 Through written words. Through text. Through computer system. Through sign language.

11:45:11 Through high-tech and low tech communication devices. What their wishes are in terms of medical support.

11:45:18 So when we think about support ed decision-making we want to start with the five steps.

11:45:20 The first is start ing the conversation.

11:45:30 So I did a presentation with Bonnie, last night with family members in west Michigan. That is what we did in the first part of the presentation.

11:45:33 How to get the conversation start ed?

11:45:40 We want to give tools and list tools in the chat box as soon as we're finish ed with the PowerPoint.

11:45:43 You will have those before you leave the meet ing.

11:45:47 Different tools that can be use ed to start that conversation.

11:45:53 And then identify ing who is willing and able to assist and support you with make ing medical decision.

11:46:01 So again, you retain the autonomy. You get to make the choice of who you want to help you in that aspect.

11:46:07 So one example, I have a family member who needs some support.

11:46:41 Identifying and communicating to medical person personal. So this was a great choice for him and somebody who knows him well and on the same baseball legal and go to the same men's group at church together and developed a relationship over the years and perfect choice for him to make.

11:46:44 He has a system of back up people.

11:46:47 If this person can't be contacted who are the next people.

11:46:55 He had to have the conversation with this individual and say, do you have the time and are you willing and able to serve in that capacity.

11:46:57 To support me in that capacity.

11:46:59 This person said, yes.

11:47:10 We made sure in the medical records at both hospitals that it's identified who this is this person is and how the hospital can contact him.

11:47:14 The third step is planning and communicating. We had the meeting.

11:47:21 Communicated to everyone that is involved in his circle of support and communicated that to the hospital.

11:47:24 You can set up formal agreements.

11:47:37 >> : You can do this on informal base. We don't have a written agreement between this doctor and family member.

11:47:51 You can use some tools to do that. Michigan Alliance for Families has some great tools and one source we will put in the chat box before we end the meeting.

11:48:07 The last part is letting everybody know. If you're somebody who is supporting ND a congregation setting and make sure everybody at your home, staff, and manager, knows this information who you want to help you make medical decision.

11:48:11 And have the contact information and identified person ready.

11:48:21 If you're supported by a CMH or MRS or disability network, make sure they have that information as well.

11:48:31 When you're filling out an emergency contact, you want them to know who you want to contact if you have a medical issue.

11:48:33 Switch to the next slide now.

11:48:42 So a lot of times we think that this has to be really, long and cumbersome and has to be done through lawyers.

11:48:43 That is not true.

11:48:49 There are a lot of things that are less restricted than having a guardianship.

11:48:59 That can help you to identify and kind of formalize who you want to support you in different areas of your life and in the medical areas as well.

11:49:02 You can sign a release of information.

11:49:10 A lot of times with the HIPPA that say that people can't talk about your information unless you want them to.

11:49:21 When you sign that release of information you're letting people know these are the people I want to be involved in my decision making regarding medical issue.

11:49:34 When sign and release of information forms then authorize parents and other allies. Could be a friend, relative, neighbor, somebody from a place of worship.

11:49:51 So those other allies access to -- gives access to the person's medical information and legal proceedings. This helps to ensure quality and continuity and enhances supported decision making process.

11:50:07 So again, you as an individual retain the right who you want to be involve ed and use ing information form that is one of the steps in help ing to communicate to people who you want to be involve ed in that aspect of your life.

11:50:12 A next formal step and many steps in between here.

11:50:25 Would be a medical power of attorney. That is a legal document in which you appoint an agent to make health care decisionings on your behalf and cannot make them for yourself.

11:50:35 An example might be I had surgery and unconscious for several hours of time. I did a medical durable power of attorney.

11:50:39 >> : Good morning, everybody I'm sorry, I'm late.

11:51:01 >> : Durable meant a specify ed period of time and that was specify ed while I was unconscious and did durable medical power of attorney to my son who is 23. If they were complication during surgery let people know who I want ed to make decision on my E behalf.

11:51:09 He thought it was great fun and unconscious and he was going to get my hair dye and all of the fun stuff.

11:51:12 But fortunate ly he was just joke ing.

11:51:14 But it can be a very help ful thing.

11:51:22 So again, in support ive decision make ing there is no one right or wrong way of doing things.

11:51:25 It's all person centered and what makes sense for you.

11:51:41 I want ed also to kind of cover my son in that situation by formal izing. I have multiple siblings who would assume they were the person I want ed to speak on my behalf, but again, retain ing the autonomy.

11:51:44 I get to choose who that person is.

11:51:45 >> : Mary.

11:51:47 >> : There is a question.

11:51:49 >> : Okay.

11:51:52 >> : If you can read it to me.

11:52:00 >> : It doesn't -- there is not a question. JJ is say ing he has a question. Go ahead and unmute and ask your question.

11:52:12 >> : I was just wondering could you like take people off, take people off the thing and put them back on?

11:52:14 >> : Okay.

11:52:16 >> : I can bare ly hear it.

11:52:21 >> : I think you said take people off and put them back on?

11:52:24 >> : Do you mean a medical power of attorney?

11:52:27 >> : No. Like.

11:52:30 On people's behalf.

11:52:55 >> : Okay. I'm still not clear on the question. Are you asking can you choose people be involve ed and not comfortable with the way they make ing decision, is that what you're asking? Yes, that is possible.

11:52:59 Again in a situation of support ive decision make ing you retain the legal right.

11:53:03 You retain the authority and the power to decide who you want involve ed.

11:53:12 And we all have relationships in our lives. Some have stay ed with us for many, many, years and continue ed with that relationship.

11:53:14 And sometimes relationships end.

11:53:17 And maybe then you want to identify other people.

11:53:26 So again, I would recommend if you change people in your circle of support. You want to make sure that change gets communicated to everybody as well.

11:53:29 Okay. Any other questions before I go on?

11:53:31 >> : Yeah, Mary.

11:53:44 >> : This is Dennis. Sorry, I'm late. What if you don't have anybody to make that decision for you?

11:53:47 >> : I don't have anybody at this point?

11:53:51 >> : I'm single and don't have anybody to make that decision for me.

11:54:07 >> : Okay. Well, again, I will supply or have Tedra put in the chat box my e-mail information and we can talk specifically about developing those community supports that maybe able to assist you.

11:54:08 Okay.

11:54:19 >> : People you can develop a relationship at a local arc or disability network and process information and be there and available to assist you.

11:54:26 >> : Because there is no one left in my family on my side of the family.

11:54:28 >> MARY SHEHAN-BOOGAARD: Okay.

11:54:50 >> : Most of my family members have already passed on. We already got the b UKSZrial. I am concern about that, yes.

11:55:04 >> MARY SHEHAN-BOOGAARD: So, yeah. E-mail me and I can help walk you through some tools or put you in touch with LifeCourse and tool that is you can help to identify people in your life.

11:55:09 Whether it's a neighbor or place of worship and talk about that.

11:55:12 Sometimes those individuals are from support agency.

11:55:20 It's up to you to choose who you want to help you make decision in your life. In that life domain.

11:55:22 E-mail me and we will talk more off screen.

11:55:24 >> : Okay. I got it here.

11:55:26 >> : It popped up here.

11:55:51 >> MARY SHEHAN-BOOGAARD: Okay. And then even you know, the national guardianship We know from statistic many people with intellectual and mental health disabilities have guardian. And supportive decision making can be talked about and utilize.

11:56:04 This is from Michigan compile law. That guardianship shall be utilize only as necessary to promote and protect the well-being of individual.

11:56:13 And shall be designed to encourage the development of maximum self-reliance and autonomy in the individual's life.

11:56:23 So even a guardianship is supposed to help that person.

11:56:27 So if I can just interject here for a second.

11:56:40 >> : This piece of the law goes back to what I said earlier. One of your rights is to be able to hear and be a part of the decision making even if you have a guardian.

11:56:42 >> MARY SHEHAN-BOOGAARD: Absolutely.

11:56:55 And the mental health code indicate you might have a guardian you're still entitled to a center plan if you're involved with the community mental health.

11:57:03 Just because the person has a guard YAN doesn't mean you don't have any say in your life.

11:57:12 >> : I think that is very important. A lot of medical decisions could easily be seen and gotten made without that person's input.

11:57:15 >> MARY SHEHAN-BOOGAARD: Absolutely. All right.

11:57:19 >> : So who to contact if you need help?

11:57:23 >> : My e-mail address will be posted in the chat box.

11:57:30 >> : Jan, do you want to go over these and while you're doing that I'm going to unshare my screen.

11:57:43 >> : So Michigan protection and advocacy is Kyle organization and you actually, I think his e-mail, what did you put, did you put your phone number in that chat?

11:57:51 >> : Kyle put his contact information. That is an organization that you can go to.

11:58:03 When you feel like you need assistance make sure your rights have been honored.

11:58:13 If you feel your Civil Rights have been violated and file a complaint with Michigan Department of Civil Rights and have an 800 number.

11:58:20 This will be in the chat. This will be somehow available to people with the phone number, is that correct?

11:58:26 >> : The recording of the webinar as well as the presentation will be available on the website.

11:58:27 >> : Perfect.

11:58:28 >> : Okay.

11:58:31 >> : Okay. Thanks.

11:58:44 >> : So also, let's say you just need help with someone to help advocate with you or talk to you figure out what your rights are and how do you exercise those rights?

11:59:16 If you have a Center for Independent Living or a local chapter of the The Arc they are amazing resources. If you don't have a local chapter both the Disability Network and Center for Independent Living as does the The Arc and those are places that you can go to get some individual advocacy to assist you should you feel you're not getting what you need or your rights are being violated.

11:59:17 So.

11:59:21 >> : I like to add to that, it's just so important to speak up.

11:59:37 I took a family member to the hospital for a scheduled appointment during COVID-19 and literally when I drove up somebody came out with a gown and mask and face shield. I got him. You can go.

11:59:56 I was like whoa, the family member turned around in total panic. We haven't talked about that. I was unclear they didn't think I was going to be staying with him through the process.

12:00:00 I had to get out of the car and have a conversation with the person.

12:00:04 And had to get three different people from the hospital to come out.

12:00:14 And that that conversation before they said, finally a doctor came out and knew me and present when I was there with my family member before.

12:00:18 And said, she can come. She can come in.

12:00:32 So you know, I put, they glove ed me and gown ed me and able to stay through the whole process.

12:00:47 Don't be afraid if you get it and from a health care provide er and give a little push back. We will give you a moment to speak if you had any experience like that.

12:00:54 Sometimes you have to be a strong advocate or have a strong advocate with you.

12:01:00 When turn ed around and look ed at me, I know means take it away. I don't know what to say to this person.

12:01:08 I'm not going in by myself and handle it.

12:01:13 I'm going to share my screen brief ly and show a COVID-19 disability form.

12:01:18 It's just one form that can be use ed.

12:01:19 Okay.

12:01:24 I'm going to make it a little bit bigger on my screen here.

12:01:31 This is one form you can fill out ahead of time know ing you're going to the hospital.

12:01:39 How to best communicate and think about support ed decision make ing in medical I guess situation this is one type of form.

12:01:45 You can take this and this works for me and move it around and do whatever you want with it.

12:01:54 We can provide a link to this for you in the chat box or if you e-mail me, I can send you an electronic cop my of this.

12:02:09 So again, this is a way to take support ed decision make ing after you make a decision and a tool you can use to communicate your choices when you're in a situation.

12:02:17 You can ask to be on file and part of your medical record.

12:02:20 All of that is steps you can take.

12:02:23 >> : I would like a copy of that.

12:02:26 >> : Dennis.

12:02:33 >> : My e-mail is in the chat box and e-mail me that you want it and get it out to you.

12:02:36 >> MARY SHEHAN-BOOGAARD: Another thing I want to talk brief ly about.

12:02:57 As Kyle mention ed there is not a lot of statistic specifically and how many are affect ed by the pandemic, by the COVID-19 pandemic and two states that have just recent ly put out some research.

12:03:03 We will put links to the research articles. I think it's New York and Pennsylvania might be the other one.

12:03:12 The first two states and take ing data specific to people with intellectual and development al disabilities is that.

12:03:17 They are a much higher percentage, than the general population.

12:03:31 In contract ing it. in contract ing and higher percentage if they contract it and get it severe ly and pass ing away and dying from it.

12:03:37 So when we talk about inequity that is another piece that we need to look at that.

12:03:40 Why is that so much higher?

12:03:49 Is it because people with disabilities are more likely or have a higher probability of being in a congregate living situation?

12:03:55 Is it because they may have other underline medical conditions?  
12:04:04 We will put a link to those two articles and put a link to that.  
12:04:08 There is an opportunity to get involve ed.  
12:04:12 Jan, that do you have that article.  
12:04:14 >> : You can go ahead and pull it up.  
12:04:17 >> : I'm going to pull it up and share it on my screen.  
12:04:22 >> : Some internship and fund ing.  
12:04:26 >> : It's going to take me a minute to get to it on my screen.  
12:04:29 >> : I want ed people to be aware of that.  
12:04:37 >> : So what Mary is pull ing up as she said an internship opportunity.  
12:04:38 >> : There it is.  
12:04:41 >> : Go.  
12:04:42 Okay.  
12:04:48 >> : Make up my mind, will you. Jump ing all over the place.  
12:04:51 >> : Sorry, about that.  
12:04:54 >> : Research about the COVID death.  
12:04:58 >> : So those are articles will be post ed.  
12:05:01 >> : The links to those.  
12:05:03 >> : I have to open up.  
12:05:08 >> : Look ing where I sent it to Jan.  
12:05:11 >> : I had it open on my screen earlier.  
12:05:13 >> : I just saw it.  
12:05:15 >> : Right there.  
12:05:26 >> : Okay.  
12:05:30 >> : So another staff member share ed this with me.  
12:05:34 >> : I'm going to make it as large as I can on my screen.  
12:05:46 >> : Applications are now open for the second health KWEKT academy in system transformation fellowship program.  
12:05:49 We will supply this information in the chat box.  
12:05:54 So Tedra, if you could take the e-mail here and put it in the chat box.  
12:05:59 The deadline for these applications is June 26.  
12:06:02 So it's fast approach ing at noon.  
12:06:09 But they are look ing for leaders from advocacy and non-profit organizations.  
12:06:12 Who are serve ing communities of colors.  
12:06:19 And other marginal lyse communities from access to the country participation, virtual train ing.  
12:06:21 And that train ing will happen in July.  
12:06:25 So we want ed people to have this information.  
12:06:30 This recent ly came out. Another staff had share ed it with me.  
12:06:37 And we want ed you to be aware that this is internship or fellowships are available.  
12:06:41 If you're interest ed have the information to apply.  
12:06:42 All right.  
12:07:01 >> : So it is right now 12:04. Does anybody have any questions or do they want to share a situation brief ly about try ing to access medical care in the COVID pandemic?

12:07:08 I'm going to unshare my screen and ask Tedra to put all of these in the chat box.

12:07:11 >> : Tedra has those in there.

12:07:16 >> TEDRA JACKSON: Before we move on I do want to share one other resource.

12:07:29 The national center on advance ing person center practice and systems have developed a person centered health care profile.

12:07:34 So while we're on this topic. I'm going to go to it and just share it.

12:07:37 I will also put the link to this.

12:07:39 So when you go to the website.

12:07:41 You're going to scroll down.

12:07:48 There is a couple of webinars that have been record ed that you can access.

12:07:58 And then the second thing on here is we have release ed a person centered health care profile and you can access the profile.

12:08:04 Template and ask you for your personal information.

12:08:05 Your current symptoms.

12:08:08 What medications you take.

12:08:15 And then the person send er ed. So that is all very medical model.

12:08:17 Sorry, my camera was on.

12:08:21 The typical questions that you get when you go to the doctor.

12:08:23 And then what matters to me.

12:08:29 If you have a name that you go by beside your first name.

12:08:31 What do people appreciate about me?

12:08:36 Who and what is important to me? How to best support me?

12:08:42 These are just things if you happen to get in a situation, where you are not able to have someone with you.

12:08:44 Right away.

12:08:52 You know, you might do some advocacy or done on your behalf, to make sure a support person is with you.

12:09:15 This is just another resource SPLAR to the one that Mary -- -- this is just another resource similar to the one Mary share ed.

12:09:21 Do you have a health care advance direct ive? Power of attorney?

12:09:25 DNR do not resuscitate order?

12:09:33 So it gets really kind of specific and help ing you to determine what you really want for your life and for your care.

12:09:46 So I'm going to stop share ing and I will make sure that I put link in the -- put the link in the chat box right now.

12:09:51 And I will turn it back over to Mary.

12:10:13 >> MARY SHEHAN-BOOGAARD: So I think, Jan, Kyle and I want ed to leave opportunity for people to share any experiences they might have had in try ing to get medical care in the mist of pandemic or addition al questions for Jan, Kyle, or I.

12:10:18 You can either unmute and ask those or put them in the chat box.

12:10:20 >> : I had -- go ahead.

12:10:24 >> : Thanks Dennis.

12:10:33 >> : A friend of mine, her father is a quadriplegic and had a stroke and had to be taken into the hospital.

12:10:53 Initially refused access and what we did. At a Beumont Hospital and I printed out the guidelines that the hospital had and talked to administration and gave the push back. He needs me as a support person.

12:10:57 I need to be there. She was allowed in.

12:10:59 The push back piece is really important.

12:11:02 So that is all I wanted to share.

12:11:14 >> : Unfortunately, the stories I heard have all involved the person or the family member or advocate having to push a little.

12:11:15 Please be prepared to push.

12:11:29 >> : You will even hear things like, our legal department and, you know, that just kind of makes me laugh, because we all as Michigan citizens have a legal department too.

12:11:47 So you know, you have to be willing to really speak up and be a strong Advocate.

12:11:54 >> : It happened to me at the hospital. It was about transportation up to the emergency door.

12:12:00 They were told to go in one area. And then told to go in another area.

12:12:13 When I got in there, the receptionist had to get somebody from the back of the building up to the front of the building to get me to go to the back of the building.

12:12:16 That was hard enough.

12:12:21 Because it was unclear where I was supposed to go.

12:12:27 T

12:12:29 Get looked at or something.

12:12:34 >> : That is similar could have happened with my family member situation.

12:12:49 Literally that particular hospital has a valet service and made it really clear, we kept moving up the chain of people coming out to talk to us before they would take him in.

12:12:50 Or go with them.

12:13:05 And so they have valet park my car. And advocate what your needs are and what are my needs ahead of time and prepared for those situations arise.

12:13:10 Any other questions or people who want to share what their experiences have been.

12:13:16 >> : I have a question for you guys.

12:13:22 That being said, how far can you push it until they say no.

12:13:28 >> : Sometimes you don't want to push it so far. You know, what I mean.

12:13:38 >> MARY SHEHAN-BOOGAARD: I guess a lot of that is your choice about your life. It would depend for me if I were making the decision how critical the procedure was.

12:13:43 If I'm dealing with heart issues right now and need to get in there as quickly as possible.

12:13:56 And maybe the person and advocate and push on their own and meeting with medical personnel.

12:14:15 My family situation had going in and months before COVID for testing and so it wasn't critical that he had it right at that moment, but it did take some strong advocacy to make it still happen rather than having to reschedule at a later time.

12:14:27 >> : So at the very begin ing on March 13, I think the day before or two days before governor place ed everybody at stay at home order.

12:14:32 I was at a hospital with a friend that had disability and communication.

12:14:50 People can't understand him when speaks and having surgery at henry Ford. On March 13 he had the surgery and asked, he had asked and the doctor had asked that someone stay over night with him the first night.

12:14:51 We had that plan ed.

12:14:53 That was all plan ed out.

12:14:57 And I was the person he asked to stay with him.

12:15:06 And then, on the morning of March 14 the hospital start ed send ing away visitors and lock ing down the hospital.

12:15:09 Even before the judge's order.

12:15:15 And someone came into the room and let my friend know I was maybe going to have to leave.

12:15:26 >> : He was fully prepare ed for me to get arrest ed. Rather than not leave the hospital. I don't know if I was prepare ed to get arrest ed.

12:15:41 He was very adamant that I be there to help him with the communication. The surgeon need knew I need ed to be there.

12:15:42 I got to stay.

12:15:46 However, I didn't get to leave the room for any reason.

12:15:53 So I spent nine days in the hospital with Izzy as the person at bedside.

12:16:09 Those of you who might be designate family member, friend, advocate, you want to know, you might be prepare ed to have to stay there in the hospital with the person the whole entire time without leave ing, which is okay.

12:16:11 Here is a question for you then.

12:16:22 >> : Are they allow ed to tell you you have to leave since advocate ing for somebody else?

12:16:28 >> : The person has the legal right to have me there. They are not allow ed.

12:16:42 One of the things that we fought for and got certification from the state. They can't tell the person, the individual that is help ing the person with those decisions or help ing them at bedside. Can't make them leave.

12:16:49 I wasn't really going to be arrest ed. Izzy thought it would be cool and funny.

12:16:52 >> : It's a badge of honor, Jan.

12:16:57 >> : Yes, I indeed. He want ed me to have that badge.

12:17:03 >> : Luckily Henry Ford Hospital let me stay. It was all good.

12:17:18 You know, you're true advocate when you've been held in contempt court or hassle ed security in a hospital and fight ing against guardianship. It's a badge of honor.

12:17:20 >> : Indeed.

12:17:34 >> : Okay. Any other questions or individuals who want to share information about experiences they've had with hospitals or doctors. ?

12:17:39 Can I just have a copy of everything that was said and done today.

12:17:42 >> : Sent to me.

12:17:44 >> : To e-mail.

12:17:47 >> : Okay.

12:17:55 >> : If you send me an e-mail with a request I will send you a copy of all of the links and the PowerPoint as well.

12:17:56 >> : Okay.

12:18:01 >> : Anyone else?

12:18:10 >> : Kyle, Jan, anything you want to say in a wrap up?

12:18:14 >> : I'm very happy that so many people were able to be on the call.

12:18:29 And just, you know, I can't stress enough how important it is for people to know what their rights are. You are entitled every bit as good as medical care of the rest of the citizens of the United States.

12:18:38 You know, it's important to bring around the circle of people that you know and trust to help make sure that can happen. We all need to do that.

12:19:08 >> : Yeah. I just want to reiterate that if any questions pop up on this issue or real disabilities issues I hope you give Michigan protection and advocacy and we have information available for folks. If you have questions about what your rights are otherwise and think of us and feel free to give us a call in order to get that.

12:19:12 You know, that kind of clarification.

12:19:29 >> : I would like to add one more thing. The self-advocacy of Michigan and have a page and post information what your rights are and rights for medical care and also other areas of your life.

12:19:38 That might just be a good Facebook page, self-advocates of Michigan.

12:19:49 >> TEDRA JACKSON: Thank you. That is a good point, Jan. And include Self-advocates. A link to their face book will be include ed.

12:20:05 >> : And then I would just close out by say ing advocate. Advocate. advocate. Get involve ed. Unless we all get involve ed.

12:20:09 Read those articles that we put links to in this chat box.

12:20:13 It was just so tell ing, as I was read ing it.

12:20:39 It didn't surprise me, but sadden me, the percentages and the difference in support that people with intellectual disabilities were receive ing. And get involve ed. Get involve ed in public policy and advocate organization. And work together that is when change is going to happen.

12:20:46 >> : Have a question for Kyle? Okay.

12:20:52 >> : Here is what my -- my point of view and what I don't get.

12:20:57 When I went to the doctor only allow ed three people. Why is that?

12:21:04 >> : You mean as part of the treatment treatment or part of visit ers are concern?

12:21:06 >> : Like treatment?

12:21:09 >> : People that can speak for you.

12:21:14 >> : So, he only allow ed three. I'm miss ing it.

12:21:27 You would have three people as patient add VOE cats and three folks limited to you.

12:21:31 >> : Three people talk for me while I cannot talk.

12:21:39 >> : I think what he is say ing, that he can only have three people to speak on his behalf.

12:21:48 >> : So as far as the limitation of the amount of people that you could have designate as a patient advocate is that the concern?

12:21:51 >> : Yup. Yup.

12:22:07 >> : Was there a greater need for more than three people as far as availability? Was that the problem that the three folks weren't available and wanted to get an additional person because of lack of access to those three folks?

12:22:11 >> : I was going to put my other family member, too, but I couldn't.

12:22:27 >> : Typically, the way, a patient add VOE cat designation you would designate a specific individual who is going to be the person guide you and make the decision in the event that you would lose capacity.

12:22:41 And typically you will see in the system and have someone identified. I don't know, of any limitation that wouldn't allow you to identify the successor down the line of three.

12:22:52 Set up a priority for who is going to fill in the role and designate one person. And unavailable and the other person will be designate to fill that role.

12:22:59 I couldn't tell you if anything that would restrict you from listing a hundred people.

12:23:32 What the documents would do is designate a priority for those folks if for whatever reason the patient advocate is unavailable or fulfill those deutos patient advocates set up for a successor. Ideally who is familiar with you and situation and familiar with the medical history and can kind of assist and support ing. Under the patient advocate.

12:23:39 Typically you wouldn't have four people making a medical decision because that would require consensus.

12:23:58 If you're unable to do and need a person to do that, obviously nothing prevents you from consulting with as many people general or wanted to do that with folks on health care and financial purposes and any kind of decision.

12:24:29 Being able to consult with those folks. As far as transferring the authority to make the decision, I can see maybe problems having four people designate to make a determination. What if two people wanted to do one thing and two people wanted to do the other thing and have a problem with people making the decision. If that makes sense?

12:24:34 >> : Wouldn't that be like having a power of attorney? Wouldn't that be better?

12:24:59 >> : It's very similar to a power of attorney. A patient advocate designation is not going to convey your right and set up to designate a person who can assist you making a decision and in the event you were to lose capacity and sometimes they do for subsequent decision making. Where durable power of attorney is going to be written up.

12:25:07 I lose my capacity this person will step in and be making financial decision or medical decisions or whatever you wanted to give up.

12:25:15 In other words, the power of attorney is going to spring into effect and not take into effect until you lose your capacity.

12:25:35 That patient advocate form, typically this person is here to assist me in making these decisions and sometimes you can include revisions that would go into effect if you were to lose capacity and going to into a coma. I want this or don't want this.

12:25:55 The patient advocate is someone going to be you consult with. I guess it's more comparable to supported making decision than a guardianship. You still

maintain your right to maintain the medical decision and have designate someone to assist you with it.

12:25:58 >> : I think we're close to wrap ing up.

12:26:01 And bring us all back to what I said in the begin.

12:26:37 Which was talk ing today about people's civil rights and you know, one of the things that Mary talk ed about is some of the research where they are find ing people with development al disabilities, where they are track ing are, COVID more frequent ly and get ing sick er and pass ing away than people who don't have intellectual disabilities and similar to what we're learn ing about after Africa Americans and their incidence of COVID as well.

12:26:48 -- -- and to other things that create a good quality of life right.

12:26:54 Then can help you be less susceptible to ill ness.

12:27:02 We are talk ing about your civil rights and Mary comment advocate. Add VOE cat. And advocate some more.

12:27:20 Are more very important comments and we should all just think about what role we can play in push ing forward pass COVID and don't have to fight for medical care.

12:27:32 >> TEDRA JACKSON: Great. Points. Jan. I think that is a good note to end on. Again, thank you all for join ing us today to get information about this very important topic.

12:27:38 Again, my apologizes about the mix up with the Zoom link.

12:27:48 I'm not quite sure what happened. But I'm glad we were able to get it handle quick ly and still have the webinar today.

12:28:07 Next week we will be talk ing again about person centered plan ing and structure ing your day and what do you need to really be considering as post-COVID. We know that everything is not going back to normal.