CFILC

Disaster Strategies Coalition Meeting

Preparing for Hospitalization Practical Tools And Solutions For People With Disabilities In Atypical Times

REMOTE CART

11/12/20 1030am – 12:00pm

>> MEGAN COWDELL: Good morning everyone and welcome to our California Disaster Coalition Call. I will get started with logistics. We have captioning on the second and fourth Thursday. Captions are available on Zoom. You could navigate down to your Zoom tool bar. And if you don't see the caption button, it is probably nested under more. And what you are looking for is the option that says show subtitle. I also just shared the link for StreamText in the chat if you prefer to follow along with captions separately. And then today I will be screen sharing a PowerPoint. So, when I do that, you will have the option at the top of the screen to go to side by side mode which will put that vertical slider bar and allow you to increase the PowerPoint size or the video feed size. And since we are in a Zoom meeting, if you do want to only see folks who's cameras are on since it could have a lot of little pictures for everyone who's camera is not on, you could hover over somebody's video and click hide non‑participants and that will make your view clear. If you have questions today, send them to us in the chat. I think we will only be answering the questions at the end of the presentation. But please send them to us at any time. And I will go ahead and pass it back over to you now, June.

>> JUNE KAILES: Thanks, Megan. Welcome all of you today. We're going to have an exciting call and I wanted to just alert you to a few things. One, Megan is going to post the link to an evaluation of today in chat. And we learn a whole lot from you. So, I know some of you have to drop off a bit early. So, if you could capture that link and give us your feedback, that would be most appreciated. Also kind of a preview. The type of calls that are in planning stages that will be coming up in the next few months second Thursday of every month, one is about legal wins and realities regards healthcare, rationing and visitation. Another is what does it take for people with disabilities to put together a quality, real and personal preparedness plan. A third one is going to be about homelessness and disability and discussion about room key to home key, COVID‑19 issues, cooling and warming centers, personal assistance and IHSS all within the COVID environment and where are we. We are also looking at some user around long‑term recovery and about effective and efficient use of social media before, during and after emergencies. So, we welcome your input ‑‑ we welcome your input for more ideas as to future calls. So, today we have a really exciting and very relevant panel related to preparing for hospitalization, practice tools and solutions for people with disabilities in atypical times. The atypical times kind of being an understatement for what's going on here right now. So, feel free to post your questions in Zoom ‑‑ in chat. I'm sorry. And we will have a good hour or so to have a good discussion after the presentation. But feel free to post your questions as they occur to you. If that is not comfortable for you, we will also be taking questions by you raising your hands and you do that through the participant list. There's a hand raising icon and we will keep an eye on that as well.

So, I will turn the panel over to ‑‑ I will turn the presentation over to Sarah. You're first. Is that right?

>> SARAH MARSHALL: That is correct. Thank you, June.

>> JUNE KAILES: Okay.

>> SARAH MARSHALL: I think we will start by doing a quick round of introductions from all of us. My name is Sarah Marshall and I'm from Madison, a speech therapist. It is cold and the afternoon and we are expecting snow. I do provide some inpatient consultations. But my primary role as a speech pathologist is an outpatient clinic who use AAC. And so, my portion of the presentation today will be talking about how to prepare for a hospitalization and all of the work we do before we get there in hopes that we don't, but so we know we are ready in case that happens. Karen.

>> KAREN TURNER: Hi. I work at Mass General Hospital. I'm a patient advocator and I have a background as an occupational therapist. My role here at mass General Hospital is really just to help people with developmental disabilities access their healthcare so I can support them in any locations in which they are here. Whether it be in the emergency department, inpatient, coming for surgery, et cetera. So, I have been involved here at MGH but also larger within our system and somewhat across some hospitals across the state too. Just to think about how we make sure that individuals with autism and developmental disabilities, which then translates to other disabilities too are able to access the healthcare that they need during this time. And I will turn it over to my long time colleague here at MGH, Rachel.

>> RACHEL TOWBIN: Hi everybody. My name is Rachel Towbin. I'm an inpatient speech language pathology gist in Boston, Massachusetts. And I completely do inpatient care so I see patients when they are in the hospital, on our neurology units, trauma surgical, general medicine units for speech, language and swallowing evaluations. Also under our umbrella doing evaluations for AAC as Sarah mentioned before. And hoping to sort of improve patient provide communication for patients who have complex communication needs. And I'm very happy to be here with you today.

>> SARAH MARSHALL: And Megan, would you be able to share the slide show, please. Thank you. Great. And as June said, the title of our presentation is preparation for hospitalization, practical tools and solutions for people with disabilities in atypical times. You can advance the slide. So, we have about an hour and a half together. Karen, Rachel and I hope to deliver our presentation in about 30 minutes and allow an hour for discussion and Q&A. We are excited to talk with you all more at the end of the presentation. Our objectives today are to discuss and describe tools and strategies to help prepare for a hospitalization, increase our awareness of regulatory standards and describe the tools and strategies you could use if you find yourself or somebody you work with hospitalized. Next slide. So, I'm going to get started talking about that proactive planning and why it matters. Almost the entirety of my presentation is referencing Sarah Blackstone and Harvey pressman's Carl. If this is something you are interested in, I would encourage you to read the entirety of the article. It is excellent information. What we know individuals with complex communication needs are at risk for communications breakdowns. Why is that? There's a difficulty with communication and the other areas we will folk on is that there is often limited preparation and then there's poor ‑‑ there can be hoar hospital staff awareness. It is important to address this because when we are better prepared, that leads to better outcomes. Something I want to mention as well is that people are facing communication breakdowns currently due to COVID‑19 who didn't have complex communication needs coming into the hospital. So, we know that COVID‑19 results in difficulties breathing and often requiring intubation. They have a change upon hospitalization in that ability. I will focus a lot on tools for AAC that people who have baseline communication impairments might be aware of. Some are applicable to those who don't have the baseline impairments still to prepare in the event that what we hope doesn't happen does and we find ourselves hospitalized. The required steps for proactive planning is indicating staff on the value of AAC and preparing individuals with complex communication needs in advance. What we have time to focus on today is how to prepare. So, that is what we are ‑‑ [indiscernible] on the next slide, please. If this is an individual who has an individual device I would encourage including medical vocabulary. I work with pediatrics through adulthood and we start instruction on health literacy early. Making sure that vocabulary is available and that instruction on how to use that vocabulary is provided. Some examples might be medication names and purposes, procedures that are frequent, daily cares and instructions on how to complete those. I have some individuals who actually have videos of how they prefer or require that their cares be provided directly within their communication device so when there is a change in staff, the individual can be autonomous in providing that training. Of course, pain type, location, severity. And then next slide. Another thing that Sarah and Harvey recommend is a medical passport. This is actually just like a paper card that you can keep on your person that is going to go with you. And when I think about what would be important to include on a medical passport, it is anything you might be communicating verbally as you enter a hospital or emergency room. Your preferences, need for an interpreter. Any medical information. Allergies. Your insurance information and then contact information. Do you have an advocate or a power of attorney that the hospital should know about and your primary care doctor. On the next slide I have a picture example of what this could look like. There's a link there on the slide to this example. But if you just Google, medical passport, there are hundreds of examples you could get an idea of what might work best for you.

Next slide. Okay. Another recommendation is developing a grab and go bag. This doesn't have to be the physical bag, although it can be. It could be a backpack. A wheel care bag or you could keep these on a USB flash drive and ask someone to print them upon admission. Some ideas that could go into a grab and go bag and I will have picture examples of these on future slides include description of any communication strategies you might use. Maybe asking individuals to speak slowly or write down choices. Maybe the technique of partner assisted scanning if that a applicable and how the communication partners can really support you in being successful. Any health related communication boards. Particularly if you do not or the individual doesn't already have a communication device or any communication boards. There are related boards available that I will show you that you could print off and prepare. If the individual does have baseline communication impairment, you could take screen shots or use the desk top editing software to print off communication boards directly from the device and laminate those to have available. You may consider including a list of assistive technology. Things like glasses, hearing aids. If someone was to go to your home to find your glasses, they would know where to find those. Your legal information. Power of attorney, advance directives. Wall signage. We will go through what that looks like. And extra charger for any assistive technology that you use that would need to be charged. Next slide.

Here's and example of a communication board. This was developed specifically in response to COVID‑19 by the patient‑provider communication task force. There are a variety of boards with different grid sizes, some text based, some picture based. Pediatric and adult. Some more medical decision‑making and these are things if your hospital isn't familiar with these boards, or doesn't have access to them, you could print them off ahead of time and bring them along with you. Next slide.

And we talked a little bit earlier about communication partner instructions and this is another example from the patient‑provider communication website. And what you're seeing on the slide is an example of ‑‑ or instructions for a communication partner of how to execute the communication strategy of partner assisted scanning. So, there's both written instructions and visual instructions to assist a communication partner in using a communication board that you may not be able to point to directly yourself. Next slide.

And this is just another example of something you could prepare ahead of time. Many hospitals do have a version of a pain scale in hospital rooms. But it never hurts to bring your own. Especially if you have a particular pain scale that you are successful using. This is an example of one that is free to download again from the patient‑provider website. Next slide. And here's an example of some wall signage that you could include or even just picture representation of how you like things to be positioned or how you need things to be positioned for you. This particular individual used ‑‑ you can see here it is hard. There's a lot of black. But on the head rest of that wheelchair is a modular hose mound and a switch he used to control the nurse call. In his grab and go bag were pictures how that should be mounted to a wheelchair or cardiac chair as well as pictures how to be mounted to a bed. If there's particular positioning of your body or equipment, it never hurts to include those images as well. Next slide.

And here's some more wall signage that I mentioned. It might be important to indicate how you communicate yes and no. Or even some basic advocacy that is so crucial. The sign here on your left with that red border it reads, please talk directly with me to include me in my medical care plan. I am capable of my decision‑making and would hike to be involved in discussions surrounding my care. So, really letting everybody who comes into that room know that I might not be speaking verbally or I may have a physical disability, but I am my own power of attorney and I want to be making my decisions myself if that is the case. If there's a power of attorney present, you could put that information on the sign instead. Next slide.

Okay. So, you have all of these tools. How do you prepare to use them? Something that I do a lot in therapy with individuals is role playing. It is important. You don't learn to swim when you're drowning. It is important that we practice these tools in low stress settings when you're not sick, you're not stressed, you're not alone in a hospital. One thing if you are a communication partner doing this role play is to anticipate questions, needs, discussions and decisions. And the best thing you could do is really sabotage the communication interaction or practice a communication breakdown. So, play that nurse who just can't understand what you're trying to say and then provide the individual with the disability with support to learn how to repair that breakdown or maybe get the message across another way. This is a really great tool. Especially for children in teaching resiliency and communication and ways to identify when your partner might not understand and what we could do about that.

And it is important to practice not just face‑to‑face communication, but how well non‑face‑to‑face communication look. Will you still be able to access your cell phone or your email in bed? Or what type of mounting solutions or other tools might you need to be able to communicate with people who aren't present? Next slide.

Okay. And then there's also some proactive planning I would encourage you to consider with your hospital. If you know which hospital you will be going to in the event of an emergency, it could be helpful to call ahead of time and just ask some basic questions and perhaps have some things documented in your chart. For example, you might want to describe or have documented your disability, any needed accommodations, communication methods, support staff and advocates, people to contact for help. Any medical decision makers, things like that.

And I see a question that I think is more applicable to address right away. The question was please describe partner assisted scanning in more detail. I will just describe that while it is fresh in everyone's mind.

If you could go back, Megan, to the picture of just the communication board, I can kind of talk the audience through that. That one. Perfect. So, when we think of a communication board, we often think of the individual just pointing to it with their finger or their hand. But if somebody is weak or unable to use their arms or their fingers for another reason, it is possible to still use that communication board through a technique called partner assisted scanning.

And so, really what we do first is the communicator, the individual, we want to establish a clear yes or no response so they could signal their message. And the caregiver would wasn't to the first row. Suction, what is my status, call my family. They will point to that row and ask the communicator or the individual, is it in this row and wait for the individual to signal yes or no. If they signal no, we would go to the next row. If they signal yes, now the communication partner can say do you need suction and wait for a response. Are you asking about your status and wait for a response. And you're going to continue to go through each option row by row and then item by item until the individual indicates, yes, that's my choice. That's my message. Does that ‑‑ I hope, answer the question? All right. Megan. Sorry I'm putting you to work. Go back to where we were. I think it was questions to ask your hospital. Perfect. So, some additional questions you could ask prior to a hospitalization would be how will staff be notified of my communication method? Is it documented in my chart or will I need to bring a medical passport? Is there a patient advocacy or social work department and how will they be notified when I arrive? What is the visitor policy and is that different right now given COVID‑19? Will staff be trained to support communication and if so, how? And then will I have access to my person AAC tools? So, if the individual is using a communication device already, can that come with? Does the hospital have its own? What does that look like? And then I think I have one more slide. An important one is what nurse call options are there. We know particularly when we're really weak, might be intubated, traditional calls can be hard to activate.

[Dog barking]

>> SARAH MARSHALL: Can I post wall signage? We have discussed how that might be helpful. Can you put things on the walls. Some hospitals may say no. Are there professionals with expertise in AAC and if so, how will they notify I'm a new patient? With that, I will turn it over to Rachel to start talking about what happens when you arrive.

>> RACHEL TOWBIN: Thank you, Sarah. That was an excellent review of the proactive measures you could take prior to your hospitalization that is really helpful and we will touch upon those periodically as we go through the next few slides. I wanted to just sort of take a step back and tell you about sort of the perspective that we're coming from. As we stated before, Sarah and I are speech‑language pathologists and Karen has a background in occupational therapy. And we come from these larger teaching institutions. These larger hospitals. And while we don't know the exact systems that you guys ‑‑ that the audience here typically interacts with or the specific policies of your systems, the information and the strategies Karen and I will describe here, we're really hoping are general enough where you should be able to apply them to really any acute care hospital you might find yourself in.

And another thing I want to bring to everyone's attention as we get rolling in this portion of the presentation is that healthcare providers are always doing the very best that they can. Do things always work out well? No. And I think that is just the reality.

[Sirens]

>> RACHEL TOWBIN: Please excuse the sirens. The office I'm in is right at the front of the hospital. What I can certainly say is all healthcare professionals really always do want to do the right thing but they might not know what the right thing is for you. And within the context of COVID‑19, they might actually have less time to figure that out. And so, if you can come into a hospitalization prepared with these proactive measures that Sarah described, that can be so, so helpful to the healthcare providers. I know from personal experience when I have worked with patients who come in with a communication system and they say this is what I need, this is what works for me, it is so wonderful to know that, hey, this patient has a strategy, a plan that works for them. And then we do our best to make that ‑‑ to make that common knowledge for the healthcare team so that anyone who interacts with them can really implement that.

So, what I'm going to do now is move forward. Next slide, please. In talking about ‑‑ sorry about that. My screen changed. I'm going to talk about just some regulatory supports that I think it would be valuable for you to be mindful of. There is an organization called the Joint Commission on Accreditation of Healthcare Organizations. It is more commonly called JCO or the joint commission. This is an organization that evaluates healthcare organizations and really aims to inspire them to excel in providing safe and effective, high quality care. And they also have very specific standards of care. And one of the sections of their standards of care really focuses on supporting effective patient‑provider communication.

And so, in this slide and the next slide I have highlighted just a few sentences from those standards of care just to really drive home to you that this is something that should be a standard of care in most inpatient acute care hospitals. You see we have effective patient‑provider communication is necessary for patient safety. Identifying the patient's oral and written communication need is essential. Next slide. The hospital effectively communicates with patients when providing care, treatment and services. And communication needs may change during the course of care. So, again, this just highlights that even though we all may be in different hospital systems, there may be smaller hospitals, larger hospitals, all hospitals should be striving for this standard of care which is that we're really wanting patients to be able to effectively communicate with their care team.

Next slide. Now, we're going to get sort of into the nitty‑gritty now of strategies that we thought could be helpful when you are hospitalized. And Karen and I thought it was best just to begin right at the start of the things when you arrive at the emergency department. And before I go into these bullets, I want to sort of highlight to people what an emergency department experience might be like. So, emergency departments for those who have been there, they are busy. They can be loud. There can be lots of beeps and it is just a very busy environment. And I think during this pandemic that can be amplified. Some emergency departments in hospitals are working at capacity and so arriving in an emergency department right now can be ‑‑ it could an overwhelming experience.

And so, for that reason, like I said before, going back to Sarah's proactive measures that she described, having those things in place are going to be really important when you're walking into an environment like that. So, some things you could do right when you get to the ED are working with your nurse to ensure that your belongings are labeled and also documented in your chart. And that is especially important for things like a communication device that is your personal communication device and you're bringing to the hospital. Hearing aids, glasses, anything like that. You want that labeled and documented.

And ‑‑ everything okay? And also making sure that you have those documents that Sarah had talked about. So, power of attorney, signage, any sort of communication documents. Either having your support person have them or you having them on your person. Having those with you will be really valuable. Finally, thinking about that environment that you're in, in an emergency department. It could be quite loud and if you are someone who would benefit from having a quiet space to improve your ability to communicate and you find that you have oddly been positioned on a stretcher in a hall, ask your nurse if it is possible for you to get some sort of space that is a little bit more quiet and a little bit more private. It is always worth asking. Next slide.

Okay. So, the next strategies I would highlight for you are to make sure that you share your documents with your doctor and your nurse and really explain their importance. In the ED, things have very fast paced. And so, sometimes taking that moment, whether it is you or your support person to really explain their importance, that can drive home the point at the very beginning and be very useful throughout your stay in the ED or your admission. And finally, I would also ask about any other services that can be ordered by the physician right off the bat that could be helpful to you. This could be contacting the disability advocacy office, if you have that at your hospital. Social work department, rehabilitation services and chaplaincy. These services can be really good advocacy type departments for you while you are in the hospital. I think especially when maybe visitor policies can be a little restrictive, these are the kinds of healthcare professionals that could really be a benefit and sort of help you to reach out to your support people, your primary care physicians and so on. And I'm going to pass the baton now to Karen and she will talk about the admission.

>> KAREN TURNER: Thanks, Rachel. I just wanted to address, I saw June bring up a question how wise is it to bring AAC and other devices like hearing aids, especially during these COVID times, tab lets, et cetera. I thought I would address that. I can understand people would be worried those items could be lost. At the same time, I think anything that is going to help to improve your ability to communicate, but also your comfort as well and making sure that you're not confused or don't feel confused, that things are clear to you, whether that be visually or auditorily I think is very important. If you do develop COVID and you do require a hospitalization, some people with more severe forms of COVID can develop a condition called delirium which really is just most characterized by confusion.

And one of the things is that is most helpful when you are confused is to have your other senses that are intact be as accurate as possible for you. And so, for example, you know, having your hearing aids, having your glasses, having whatever you would use for communication, those things are very supportive to healing from having delirium. I think the idea of making sure it is labeled, making sure that it is documented but it is with you, hospitals aren't required to replace devices if they are lost. But it is always important to, if you do have a lost device to work with the hospital to see if it could be reimbursed for you, et cetera. Each hospital has different kind of policies around that. But at the same time these proactive strategies, having it labelled and documented and having a consistent place where you want to keep it throughout the hospital. If you have a bag that is always going to be with you. I know it was mentioned to bring an extra charger if you have multiple devices. Bringing your own charger and an extra charger is great even for having a singular device as well. So, that if your device does need to be charged, it doesn't need to be removed very far from you in order to do that. Just wanted to share those things as things to think about when you think about what you want to bring with you.

Rachel started us off with arriving to the emergency department. And I'm going to pick up with being admitted to a unit. And so, some of the questions that you can ask or that hopefully you have an answer to the first one here when you are first admitted is can my support person remain with me? Support persons are considered a reasonable accommodation. But I also know that visitors policies are overseen by the hospitals and hospital systems. My experience and my best advice for you related to having a support person be with you is be very specific as far as the clinical ways a support person is going to help you and the staff taking care of you. So, for example, you know, with the individuals with autism that I work with, they may ‑‑ many of them have a slow processing time in which they need more time to understand. Or they have really specific words or language that needs to be used with them. And so, for their support persons we were able to make a case in this very clinical context, in order to understand what you want them to do, in order for me to be able to tolerate wearing a mask, to be able to understand the steps of a procedure, I need my support person to help be my kind of translator in a way.

And it goes not just for communication, but also, you know, emotional support. You can make the same kind of arguments for, you know, if you have a mental health condition in which your ability to communicate deteriorates significantly when you are under a lot of distress. You can again make that same kind of argument. But, again, think about, you know, the ways in which that support person can clinically improve care for you. We could always talk about that more in our discussion if I'm not being clear, giving good enough examples. This idea of wall signage and I saw a comment come up that was really effective for one of the participants today in this Zoom. I have gotten a lot of feedback over my time here at Mass General just how valuable those wall signs are or signs that are visual or information being highly visible to people. Can it hang on an IV pole. Just making it as visible as possible. It is not just the nurse and doctor that needs to know these things. But the personal care attendants who may come in how to help you go to the bathroom, the people who bring your meals in, come in to clean your room. All those individuals and staff persons need be aware of what your needs are.

So, those signs could be about communication but it could also be about how you want the room to be set up in a particular way or the things that are most calming for you. Like maybe having a warm cup of tea and a warm blanket would be highly comforting for you. Those are all things you could consider putting on your own wall sign. And then, finally asking about alternative masks. In particular, clear masks. I have an example to show you. I took the strap off to modify another mask. But this is an example of a clear mask that is available for hospitals to have. And it is not an N95. It would not be able to be used in the context of a person who is COVID positive. But if you had a hospitalization for a different condition and hopefully the hospital that you have sometimes these clear masks can make a really big difference for communication. So, always helps to ask about them.

Please advance the slide. Then thinking about your team and the people on the team taking care of you and also the plan for the day. I have had people that I work with just find it very helpful to ask if they could have a designated point person to communicate with. So, is there one person on the team or one person on the unit. Maybe it is like a social worker but maybe it is someone within nursing. The more consistent the person or the few people can be, the better. But just really so that you have one person that you can check in with on a regular basis or who could check in with you, particularly if any concerns come up too.

And then also one of the strategies that we often share here with our nurses is, you know, one of the first things of the day is just to walk into someone's room and, of course, introduce yourself. But also talk about what the plan is going to be for the day. And so, always ask about that too. You know, hey, can you help me understand what is going to happen today. That would help me to feel more comfortable and just make sure that however these plans are communicated to you, that they're communicated in ways that are most supportive to you. They may not be just verbally but also having something written down or a picture schedule or things like that.

I have some families that have prepared ‑‑ I will show you an example of different ‑‑ this goes back to the AAC idea. Have prepared ‑‑ these are what are called Johnson symbols. They are pictures on a clip. Just another alternative way to communicate. But if you are someone who really benefits from a picture schedule, it's these kinds of things that you could think about going prepared with to a hospital. And common things that we do in the hospital every day, take medications, eat meals, et cetera.

Question about ‑‑ I see a question come up about medical grade masks. You're correct. Masks have different levels of protection. Just going to make sure I'm answering ‑‑ the masks that I just showed you, that is a medical grade. It is an ASTM level three. There's also ‑‑ that just means like protection from fluids and that sort of thing. It is not the same as an N95. Although this mask here is an ASTM level three, it doesn't provide N95 protection. That is where any masks that we do have within a hospital do go through a process of vetting to make sure that they are safe.

This one got emergency use authorization through the FDA too. So, for example, here at Mass General, we age use FDA approved materials within the context of COVID. We are using any that are kind of emergency authorization use through the FDA. And so, just wanted to share that about these clear masks. There are medical grade ones as well. And there are some coming out hopefully that we're waiting for FDA approval. I will show you one really quick. This is another one that is one that we just trialed here that is made all of medical grade and FDA approved materials. But we're just waiting on the final FDA approval to then be able to order and use them. So, just to know there's lots of people out there working on the clear masks. There are also people working on N95 level clear masks. Hopefully that will be resolved soon. But I don't have any updates on kind of timelines on when those will be available. Next slide, please.

Another good question to ask. How will everyone taking care of me know what I need? I brought up this point already. I got a little ahead of myself. Are you documents visible for everyone to read and see. You can advance from here. Thank you, Megan. Ask if your medical record has an alert that indicates you have an accommodation need. So, here within our ‑‑ the system of hospitals that Mass General is in, we have something called the special needs flag. It is a feature of a commonly used medical records system called Epic. And our process is hospital registration when someone calls to be a new patient or update their record, asks if that person would like to identify as having a disability and then if so, what accommodations they would benefit from. And then the special needs flag has different categories that can be selected by the patient. So, cognitive impairment, physical mobility impairment, visual impairment, et cetera. That is just how this flag is built at a basic level with Epic. What is great about this flag is it is on the person's record. It appears right near where allergies are.

It is viewable whether you are in the emergency department, you are in an office, you are in the inpatient unit. And it is a place where we could really highlight that an individual has a disability, wants to be self‑identified in that way and also has an accommodation need. And so, I would strongly recommend reaching out to you know, your local hospital to find out if ‑‑ how they document disability. If there's a flag or some kind of alert in that way. And that documents kind of what really the most important or what are the accommodations that you need in order to access your healthcare. I saw somebody bring up about the communicator. It is true, the communicator is the only FDA approved mask right now. There are a few with that emergency use authorization. The communicator is actually on backorder right now which makes that more challenging and that is where we hope the FDA will approve more mask Secretary of State that we will have more available to be able to be ordered.

I saw a question come up about when key hospital staff person to check in daily, how common are hospitals, especially in smaller hospitals. Let's come back to this question, June, if that sounds good. I have only ever worked in ‑‑ at MGH in a large kind of urban hospital system. I have family that have been in smaller hospitals. And so, you know, I guess if your question is ‑‑ I think I need some clarification around the question. We will come to that soon. We will go ahead and forward from here.

Finally, we wanted to include a slide about addressing any challenges that come up. And so, one of the most important things I can say at least particularly from coming from a patient advocacy standpoint is to just say something immediately or as soon after the issue happens so that a resolution can be worked on. Sometimes, I think I have found some of the individuals that I work with, you know, they understand people are really busy and they don't want to bother anybody. But I just want you to know that it is very important to speak up so that we can take the very best care of you and that staff can really understand kind of what your needs are. Because in the end, that's going to be better for everyone, including the people taking care of you.

You know, if a challenge does come up, try communicating with that designated point person. Whether it be a nurse leader or your person. Don't hesitate to involve your supports from outside the hospital. Sometimes having a peer‑to‑peer conversation a physician or specialist in touch with a physician on your team or a specialist on your team can make a difference for advocating for your kind of needs and perspective. So, just wanted to kind of share that advice.

When there is an issue, you know, remaining calm and being as clear and direct about it too, it is okay to just be very direct, you know, with the language that you're using. But be persistent. Don't feel like you have to let something go if it doesn't get addressed right away. It just means there's still an issue around taking care of you that we can make better. Finally, also when you do share your concerns with someone, sometimes then it takes time for concerns to be addressed. And that time can be very anxiety provoking for people. So, asking someone to explain what the next steps will be for. Let's say I don't have a solution for the problem yet, but I can at least tell you, okay. I'm going to speak with this person and this person. Then I will come back and let you know what I learned. Even if I don't have a solution yet and then we're going to work and I will figure out this next step to take. And let's now try this together. And then you're going to let me know how it is working for you. Next slide, please.

And finally, around discharging and leaving hospital. Don't hesitate to request alternative format for discharge instruction. Maybe it is simpler or larger font like electronic format. One of the differences during this time is in the past hospitals would have caretakers come into the hospital. Have a formal meeting with the patient and whomever is supporting the patient out of the hospital. Some of that is not happening now and maybe just happening over the phone. And may even be happening separately between the person and their caregiver. So, don't hesitate to request either an in‑person, if it is like a support person that can be helpful or a virtual meeting that includes you and whomever your support person is so that the education and instructions can be presented to both of you at the same time so that everybody is on the same page together both around what is communicated and the information that is received.

And then finally, we just wanted to share that hospitals typically send surveys to people's homes after visits. And the hospitals really use that feedback to guide practice and improve quality of different things. It is very important to them. And so, I just wanted to share that it could be a very stressful time. But if you have the ability and the energy to complete a hospital survey and send it back, the feedback that you provide is just so highly utilized. And I think it is something that I really wasn't aware of until I worked in the position that I'm in. Just how influential that could be in creating change at a hospital. So, just wanted to encourage people to do that. You can forward the slide. This is the reference for the article that Sarah was mentioning earlier. And you could move on to the next slide.

And this is the link to JCO for the standards. And you can forward the slide. Okay. We will stop here for questions. If you want we could end the slide view. And come back to everyone. I know we went a little longer than half an hour. It was a lot of information. But I'm sure we have plenty of time left together to answer questions.

>> JUNE KAILES: Thank you, Karen. That was so much to think about in terms of detailing the kind of specifics any of us might need to customize for our own hospital planning. This is the time we could get a good discussion. You could use chat to post your questions or you can raise your hand in the participant list. Megan, how does one raise their hand in this list? I don't see that icon here.

>> MEGAN COWDELL: Sorry, June. I was away from my mute button. You should be able to raise your hand if you go to participants. It will pull up under ‑‑ there's a little three dots button and there should be an option to raise your hand there or you could do ALT Y. So, the ALT key and the Y key together.

>> STUDENT: Megan and I will keep an ‑‑

>> JUNE KAILES: Megan and I will keep an eye on hand raising there in chat. Again, your questions in chat are welcome.

>> KAREN TURNER: I did see someone write can you highlight something on the discharge plan from the hospital to the community? I'm happy to give some examples and then you can let me know if that answers your questions. So, it would be follow‑up appointments that you have. It would be any symptoms that could be important to be looking out for that would indicate that you need to return to the hospital. It would you what you were diagnosed with. Any testing, the medications you will be taking when you go home and the instructions for those. So, sometimes discharge paperwork can be quite lengthy and have, as you can imagine, all those different components included. Does that answer your question? Oh. If anybody is getting discharged for community placement with disability precautions. Do you mean a placement as in back to a previous living situation or do you mean a placement as going to a rehabilitation facility?

A new place in the community. Okay. Sounds like your question by disability precautions, do you mean information about the accommodations that you benefit from or that you need? Not benefit from but that you need and require? I'm kind of trying to look for help with advocating for that. Specific measures to keep individuals with disabilities safe. The discharge paperwork would have anything that would be a medical precaution to keep someone safe. You know, it might be positioning of a certain kind. You know should not lay flat. Or it could be ‑‑ let's say someone had ‑‑ was admitted with a broken leg and had surgery and now they are not allowed to put any weight on that leg. It would give what the precautions are and for how long. Those are the kinds of precautions that would be in a discharge summary from a hospital. Anything that would be medically related to that stay.

>> JUNE KAILES: I see a hand raised from Vidal Medina. Unmute yourself.

>> Thank you. This is regarding interpreters. I wonder in the larger hospitals where you three ladies work, we have a UC center here and we have Kaisers that are pretty big. This is on the west coast in California. One of the things I have been asked from my consumers is, is it appropriate and not trying to be rude to request an interpreter for physicians that you cannot understand? For instance, I was once told that some ‑‑ a physician was talking to this patient and the patient requested an interpreter. And the nurse said well you speak English very well. And the patient said no it is not for me. It is for the doctor. And I think it was an important thing. Maybe I wouldn't have asked for it that way. But it is important that because these medical centers are teaching hospitals and there is a lot of those situations that doctors are very busy. Maybe they're not understanding what the patient is saying. But more important, the patient doesn't understand. So, if the language of choice for a physician is whatever language they speak, then could the patient ask for interpreter from that physician's language to English? Over.

>> KAREN TURNER: I think so because ‑‑ so, when our interpreter ‑‑ and you two should jump in after me too. When our interpreters ‑‑ our interpreter services here are awesome and they do presentations to our departments. They say if you need the interpreter for not just to make sure you're communicating to the patient, but ‑‑ let's say the patient says oh no, I don't need an interpreter, I got this. I can understand fine. But I would feel more comfortable having an interpreter there with me also speaking, you know, the second language or the second language of the other individual, I can request that they come there for me. Did that make sense? I didn't say that in the most eloquent way. I think the opposite should also be true. That just like I can have an interpreter there to make sure that my communication is being understood by the person at a level that I feel comfortable with, even if the person who is being interpreted to says I don't need someone, I don't see why the tables couldn't be turned too. That a person could say I would like an interpreter because I feel like there are some communication barriers even though we both speak English and I think it would be helpful to try it. That's an excellent question.

>> And the level of communication is very important in healthcare.

>> KAREN TURNER: Yes.

>> Sometimes the doctor may be speaking about something and the patient ‑‑ it has nothing to do with medical terminology.

>> KAREN TURNER: Right.

>> It is just based on what the importance of something is. There might not be any inflections in the voices because of the language they normally speak you wouldn't say it the same way.

>> KAREN TURNER: Yes.

>> So, thank you very much.

>> KAREN TURNER: You are so welcome. I think that brings up how language has a cultural element to it, too. It is not just a direct kind of ‑‑ part of what medical interpreters do isn't just help make sure exactly what is said is said, but also help to keep in mind the culture aspect as well and make sure that is fully understood. Thank you. That is a great question. I don't know if Rachel or Sarah would want to add anything to what I said.

>> SARAH MARSHALL: No. That was a great explanation. My only caution would be to make sure that doctor does actually speak the other language and doesn't have a strong accent. That person may not any longer be fluent in the language that you might anticipate that they speak. And so, it is tricky. I have never had that question come up either. It is a tricky situation. But I think being open and honest with the doctor that you're not understanding and maybe asking them to rephrase or add some visuals in addition to asking if speaking it in a different language would be more helpful or natural for them.

>> RACHEL TOWBIN: I will add if you feel uncomfortable about saying that to the doctor you could speak to your nurse and say plainly, I'm having a hard time communicating with my doctor. This is, you know, why I feel that might be. And then that nurse or nurse manager can help you kind of navigate what could maybe be an uncomfortable conversation, help you navigate that a little bit easier.

>> SARAH MARSHALL: Rachel, did you see the question in the chat about the consult?

>> RACHEL TOWBIN: I did. For SLP and inpatient roles how does it typically work to consult in the ED? Do you get called to assist or what communication situations in the ED would an SLP be called on for or do you typically work with patients only once admitted? There's a lot there. So, I can really only speak to our practice at Mass General. And a consult for a speech‑language pathology evaluation can happen from the moment a patient enters the emergency department. That could be for speech, language, swallowing, voice, cognition or AAC. Now, when ‑‑ there are a lot of factors that go into whether or not that patient is seen while they are in the ED or if they are seen when they're admitted. But we do see patients while they are in the ED. Reasons why we might see them in the ED might be this is a patient that is simply going to stay in the ED or the ED observation unit and we need to get these questions answered or find these supports before they are returned to the facility that they came from or returned home. They don't require admission, but they still want our support before they discharge them.

Now, we might also go and see a person in the ED before they're actually admitted to a unit because this is a patient who the team may really, really require some assistance. In the option of AAC, the nurses say I need help. We see that this patient has these needs. We are going to put in a consult for SLP. We feed their assistance and that could be a reason we see that type of evaluation in the ED as well. Most of our consults are when patients are admitted but they do happen in the emergency department. Does that answer your question? Okay. Good.

>> KAREN TURNER: I saw earlier in the chat about having a binder that they carry with them and that being really effective. Just want to second that. I think that is a great idea. I know we talked about the wall sign a lot. But a binder, anything that ‑‑ I have a care plan here that I use that outlines not just what someone ‑‑ someone's communication needs. But also any sensory needs they have. And then also by different procedures how well it is tolerated and challenges. Does anyone have difficulty with waiting? How do they do with having an IV placed. How do they do with taking medications? What kinds of supports do they need for self‑care? All of these things could be things you document. Particularly or ‑‑ that you have in a binder. Particularly if there are things that are difficult for the person in a medical setting and if there are particular strategies that worked before.

I have one young woman who needs three people who work with her all the time in order to tolerate having an IV placed awake. But they have this system down with her with now where she is tolerating it great as long as she has them. So, kind of outlining some of those things unique to people is helpful.

>> RACHEL TOWBIN: If I could jump in. I think as a healthcare professional, I actually second the frustration of not always being able to get records that you would love to be able to see. You know, I think it would be a wonderful world if we could very ‑‑ with, of course, signed consent, we could access medical records from other facilities. Sometimes we have patients who come in and it's reported to us that they have been seen at X hospital or has been seen by a speech pathologist at this location and we would love to see their notes. It would help us. But sometimes it is not that easy and that is a frustration, honestly, on our part too. What a world we would live in if we could make that easier.

>> JUNE KAILES: I wanted to jump in here. The comment about bringing your own notebook and it is parallel to your advice about putting things on a flash drive. My experience with healthcare more recently is you can't put any thumb drive in any of their computers is not acceptable these days because of caution related to all kinds of hacking, viruses, et cetera. So, I think the notebook even though it is a throwback to killing more trees might be more resilient these days. Something that hadn't occurred to me until I was listening to this discussion.

>> RACHEL TOWBIN: At our hospital when people bring in hard paper records, typically there's someone on the unit who could scan those in to what we call a media portion of the medical record and that way at least they are in the medical record. And they can be easily accessed that way.

>> JUNE KAILES: The other thing I wanted you ‑‑ I thought Vidal's question was very important. I have been in a position where I have had to interpret for somebody who has a hearing loss because they can't understand the person's accent even though they're speaking English. And so, I think in urban settings, at least here in L.A., the diversity of the healthcare staff is awesomely broad.

So, understanding all these accents I think for some people is a difficult task. I really thought that question was critically important. And I think it also resonates for people with hearing loss to begin with.

>> KAREN TURNER: Especially when you add masks to the mix too. Now we have lost the visual cues of someone's mouth moving too that was likely very supportive prior to. I can understand.

>> RACHEL TOWBIN: I think I had actually seen much further up in the chat while the presentation was happening someone mentioned like a text to speech or speech to sort of an app. Sorry. And there are apps out there. I think one is called Ava, that can ‑‑ where someone is speaking and then the app sort of puts that into speech on the phone or on an iPad and that way you can see exactly the speech that is coming across the screen. Sometimes we use those for maybe our newly hearing impaired patients or people who are very savvy with their phones and tablets and they use them very easily.

>> JUNE KAILES: I wanted to clarify and go back. I see a couple of companies about that hospital list. One of you mentioned the importance of really checking in with that one person once a day. And I know down here my primary care doctor once said I can't go to the hospital anymore. It is just too much to make early morning rounds. So, I'm working with a hospital list and just be aware of what they do. They are my communicator and they're communicating with me all day long. I don't know how common they are or how helpful this is to consider as the person. Just want to know what your experience is with that label staff kind of person these days.

>> KAREN TURNER: So, at our hospital or at MGH, I do ‑‑ I agree that I think if you can get a physician or a specialist that has ‑‑ that sees you in the community but also has hospital privileges, that can be helpful to you when you are inpatient. Even if that person doesn't end up as part of the team caring for you, if they are there in the hospital, they may come to see you which is very nice. Or they may be able to help communicate with your team on your behalf, as you have said, June.

We do here at MGH and I don't know what they have at other hospitals but we have a service called the complex care team which cares for some of our most medically complex patients and they serve ‑‑ some of them serve as both the patient's primary care physician and their hospital ‑‑ their attending. Their lead doctor when they are needing to be in the hospital inpatient. And so, of course, that kind of care model is like ‑‑ it is wonderful because then you have ‑‑ the person taking care of you while you are in the hospital also understands all the little details around your medical dare when you are in and out. I don't know about that model in other parts of the U.S. But just to know that those things ‑‑ those kinds of models do exist and, you know, it is ‑‑ I think if you are someone who has frequent hospitalizations anyway, it could very ‑‑ and by frequent, I mean more than like three times a year even. Like somebody with five, six, eight hospitalizations a year. It would likely highly benefit you to have ‑‑ to find ‑‑ to try to get a physician who works at your hospital inpatient that could also be the primary care or specialist involved in your care in some way.

I don't know. Does that answer your question, June?

>> JUNE KAILES: Yes. I think so.

>> KAREN TURNER: Okay. I wish that we could ‑‑ I wish it was available for anybody who wanted and needed it. That's like the heartbreaking thing. Even for patients who are here, MGH patients, it is still a limited service. But anyway.

>> JUNE KAILES: I'm not seeing any hands raised in the list. So, did any of you want to add issues that you didn't get to touch upon? Including you three speakers, panelists.

>> KAREN TURNER: I think I see a follow‑up question to what do people do when they don't have any supports in the community. That's such a great question. As far as discharge and follow‑up at discharge of somebody who was maybe inpatient, following up outpatient, I can speak to ‑‑ we do have a program here with what is called and unattending nurse with the attending nurse makes follow‑up calls. But it is usually just one or two. And the goal is really to just check on the person because ‑‑ and to hopefully avoid a readmission. Hopefully the person has what they need. Everything worked out smoothly for them because when a readmission is going to happen, it usually can happen quite quickly.

And so, that is that role of the attending nurse. But as far as someone who is inpatient, continuing to follow someone outpatient, I don't know. It is not a practice that we have here. I think as far as supports in the community, I hope that at the very least you have a primary care physician. I know that supports through those offices can be very limited. I have found ‑‑ and actually, I think what is wonderful is to be a part of a community like everyone that is here today. Because it's really ‑‑ in my role, I have learned so much from families and individuals who are parts of systems who have gone through experiences themselves and have ideas around resources that are in the community. You know, there are kind of state organizations like for example we have the Department of Mental Health here in Massachusetts. We have department of DDS, developmental disabilities. I'm sure each state has varying kinds of departments like that, that can always be a place to begin.

Or even your own local community health center. And what's great, if you have virtual access. I think that is one of the most exciting things I feel like I am seeing is with telehealth as long as you can access the internet and you have what ‑‑ or you have a phone, that access through telehealth is just so very different and broadened. There's likely things that I'm ‑‑ there's actually many, many things I'm not aware of but that you could likely access even just through telehealth. So, just wanting to encourage you to keep looking around. Keep asking and especially now that telehealth is so much more prevalent.

>> JUNE KAILES: Can you all go back and talk a little bit more about the call button? A lot of people I know over the years have explained about ‑‑ have kind of complained about a lack of access to them or not being able to activate it. And the hospital not always having the kind of technology back‑up to give them something that works. Like a big button or whatever. What's the best way to advocate for call systems that you can use when you're not able to use the most common one?

>> SARAH MARSHALL: Go ahead Rachel.

>> RACHEL TOWBIN: Please.

>> SARAH MARSHALL: Please jump in. But most hospitals do have alternative call nurse options. As Rachel talked about it is a joint commission standard that you are able to signal and get help of somebody in your room. There are a variety of options. There are something called a soft touch. It is a big type of plate that you can touch. It doesn't require a lot of force. There's some squeeze balls. There's some you might be able to activate by blowing into. There's some that respond to a click or small muscle movement. Some are more specialized than others. I don't know what every hospital has that is why it is helpful to call ahead and ask.

I would imagine each has some pretty widely used generic alternative nurse calls. The best way is to ask. If you think you will not be able to press that small button on the remote control, it is definitely something to be proactive about. We could put links in the chat to nurse call options too.

>> RACHEL TOWBIN: I would add two services that could be helpful in troubleshooting that type of scenario are speech therapy and occupational therapy. Oftentimes when we are trying to find what is the best call button option for a patient, speech and OT working really closely together because we are sort of looking at ‑‑ we are each looking at the different abilities of the patient and what is going to work best for you and collaborate with nursing to also try to find you the best option.

So, those are two services you could advocate for, asking for a consultation.

>> KAREN TURNER: You can also find out for your hospital what ‑‑ I don't know what to call it. It is like a technical thing. Not technical. For example, here at MGH where you plug the call plug in is a universal plug. You could pick it up at Radio Shack. I don't think Radio Shack is around anymore. If you have a specific set‑up. You have frequent hospitalizations, it may not be that expensive of a set‑up for you to bring your own and find out if your hospital has like a ‑‑ what kind of universal plug‑in. It is always worth exploring kind of outside the box too.

And again, thinking that proactively. Could be addressed before you get there so then you don't go 48 hours without ability to use a call bell while consults are being put in and you are getting seen and evaluated and we will go find the equipment and we will be back. To throw that out there as a good ‑‑ something good if you want to problem solve outside the hospital too.

I saw the question from Bruce Morgan about the one of the problems with our consumers is many have no family or people that can go with them to a procedure. For some procedures like a colonoscopy, the hospital will not perform the procedure unless you have a person to drive you home. Even they will not accept Uber or a taxi ride. You are right. How would you suggest a consumer deal with this situation?

I'm kicking myself right now because I feel like my brain has a better answer for this and it is not coming to me. But I know this is an issue and this is an issue for things getting canceled and people not having access. What I would suggest is go to whomever is ordering the test. So, for example, if it is your primary care physician that is ordering the colonoscopy, go back to that person and say I can't to do this but I don't have a support to be able to come with me. How ‑‑ please help me figure out how to remove that barrier. Because it is true, unless you have the financial resources to briefly hire someone temporarily. What I don't know is would a ‑‑ would case management, for example, be able to arrange for ‑‑ it is not an ambulance. But a different kind of transportation. Like a medically safe transportation with then a VNA in place to check on you that evening. I'm thinking that there are ways to move around that. But I would involve the ordering provider. Yes. Good. I was on the right track. Ask your PCP to order home care assist for short term.

>> JUNE KAILES: We are almost out of time. But I wanted to thank you all for a great and detailed discussion. Lots to think about here for typical times and for COVID times. So, a lot of things we need to consider in terms of our own planning. Thank you for helping us think about this much more broadly than maybe some of us have in the past.

Just a reminder that this call is recorded and it will be posted on the disability and disaster website and it will be up in a few days along with the slides and other suggested resources that were also distributed. So, again, thank you to the three of you for your very impressive presentation and preparation and slides. It's most appreciated. Particularly for the three of you who view things from the inside. Really a big thank you to the three of you. And thanks for the rest of you for joining today and we will talk ‑‑ we have another call at the end of the month. The fourth Thursday. More of a advocacy call. But we will continue some of these issues in that discussion as well. So, thanks again and talk next time.

>> RACHEL TOWBIN: Thank you everybody.

>> KAREN TURNER: Thank you so much for having us, June.

>> JUNE KAILES: Yes. Good job.

>> Thank you.

>> Thank you so much.

[Event concluded]