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>> Hello, and welcome to our webinar follow-up from our Twitter chat, Own my Health Record. I am Adriane Griffen, the senior director of Public Health and Leadership for AUCD. I am joined today by Sherice Smith. Sherice, I know you have a lot of different hats. I'm going to let you introduce yourself and your roles.

>> My name is Sherice Smith. I am with Partners for Inclusive Communities just through the University of Arkansas. [inaudible] you said. I do have a lot of hats, but for the purposes of this, I am with the Disability and Health program, where we do health education and also prevention and evidence-based programs and also access to care.

>> Awesome. Thank you, Sherice. I think we just want to make sure I got all of your hats in there. I appreciate you doing that.

>> Listen, also working currently on a big COVID grant through partners. I wear a lot of hats, but that's the main hat right there is my Disability and Health Program hat.

>> Oh, thank you. One other hat that you wore for us was serving as a discussant for the Own My Health Record Twitter chat. We wanted to do this interview with you really as a way to share what we heard, the key themes, because Twitter chats go by very, very quickly, so we wanted to slow it down and talk about what we heard.

I know we talked in preparation for this. One of the key things that you said was, "Golly, we just need to not make any kind of--" I think you used the word "assumptions" and just be okay with

asking questions. I wondered if you could share a little bit more about that and how it pertains to health records because that's new for so many people.

>> Right. We often make assumptions about people with disabilities. We make assumptions about their healthcare. I make assumptions. Full disclosure, I have a disability, I have spina bifida. I've had a disability my whole life, but even I still make assumptions about healthcare. I make the assumption that because--

I'm in Arkansas, which is very rural and spread out. I assume because you live in a more urban area that you have greater access to the internet and things like that. That's just not always true when you talk about the assumptions people make. We assume that people with disabilities because they have a disability, then they need more healthcare or more services. That's not always true either. Assumptions was the overarching theme that I thought for the whole chat.

>> One of the other things was just around how you understand all these different terms and the use of not only just the terms, translating that and transcribing it into plain language, making it understandable, and taking for granted that people know how to use the technology.

>> Right. I am a college-educated, well-read, love reading. I have no issue understanding, but when I read a health record, I am so lost because they use these terms that the average American doesn't know. You combine that with a person with a disability who might not have exposure to certain terms outside of their disability, they have to look it up online, and there could be all kinds of misdirection and misinformation. Getting online is really dangerous trying to look up health information.

I think that's a huge problem is getting it to where they can understand their health in words that they can understand, and they're getting access to it. In my situation, I use an online portal, which is an online system that doctors, all hospitals use in the state of Arkansas, and you can go on there and look at your health records and things like that, but I also have access to the internet.

If you don't have access to the internet, you can't access it, and forget about trying to get it in paper form, where it's adaptable in terms of large print or braille or something like that.

>> Right. One of the other things that I was curious about to have you mention just a little bit more about is how you navigate all of this because there's so many layers to it and, like you just mentioned, online portals. What themes did you hear around navigating it at all?

>> Very carefully and very confusingly is how you navigate it, very cautiously because it's difficult enough going on there to access your care, but then you have to go on these different little links and then you have to go for more-- It's like a big rabbit hole. You go down one. They take you to this link, and then take you to this link, and by the time you've finished looking, you don't even know why you were even on there.

I heard a lot of people talking about using support systems, advocacy, advocates, and social workers and social services, and things like that, or even calling your nurse at your doctor's office and saying, "Look, what does this mean? I do not understand." I myself have had to do that where I said, "Listen, this is not making sense. I don't know."

My sister who is in the health care field, I call her and text her all the time. "I don't even really understand what this is. What am I looking at?" so that I know what questions to ask because if I know what I'm looking at, I don't know what kind of questions to ask so that I can be well-educated about my health. I think it's important.

>> I'm hearing you say really two things, be okay asking questions and be okay recruiting a local advocate, whoever that is, whether that's the local nurse in the office where you seek your care or a social worker or a family member, get someone to help you navigate.

>> I think asking questions is so huge because this is your health. Your health, it's so important and you shouldn't be embarrassed to ask questions. You shouldn't be ashamed to ask questions or afraid to ask questions, because even if it seems like a stupid question, it opens up the conversation I feel for the doctor or whoever it is, step back and say, "Well, maybe there's some other things that they might not even understand, but they're not mentioning."

I say, "It's your health. It's your body or your mental health. It's so important to have the conversation with people and being able to talk it out."

It would be great if every county or every state, there was an advocate that you could call and say, "Look, I need help interpreting my health records."

We all know that certain neighborhoods and certain demographics are not going to let certain people in being from the Black community. They're not going to let an outsider in to help them with anything. They want people from their area to assess because when you're talking about your health and giving people sensitive information, then you're talking about having to trust someone.

>> Trust is a huge issue. You want someone that understands you and your community and has that understanding. That makes sense.

>> Also, your health. I'm just using it, for instance, if you have AIDS or if you have another health condition that you might not want everybody to know about, cancer, whatever it is, you have to have somebody you can trust to have that sensitive information that you don't have to worry about getting out to people you don't want access to it.

>> I wonder if he could talk for a little bit about how the health record and really owning what's in there helps support you in these conversations. Because I know in preparation for this interview, we were talking about how the health record is a good resource, and it can support you because these visits, the health care and our action, the actual visit, sometimes it's really quick. It goes by fast. Could you talk a little bit about how the health record and owning it supports that?

>> It's important to know what's in your health records because if you don't know, you don't know what questions to ask. Because I was at a health care provider. I'm no longer with them, but they said, "Listen, you can only talk about two health questions. That's all we have time for."

I'm not old, but back in the day, doctors would spend time with you, sometimes 30 minutes or an hour, having conversations with you. Now, they're chronic crank outpatients as quickly as possible. They say, oh, you only have answers for two questions, so make it good basically.

You have to know your health records and have to be able to understand it so you know what to focus on basically. With the person with a disability, that can be unrealistic to ask them to, say, focus on two things, when you have five things happening at once or whatever. I think feeling supported in that and knowing what you're supposed to know and what questions to ask. I often encourage people to have questions written down once they're going to their doctor so that they don't forget anything?

>> Yes, that helps support you getting the care you need right now, not next visit when you're allowed to ask a couple more questions, but getting it in. How do you think owning your health record supports people with disabilities story emergencies like what we're dealing with now?

>> I did a webinar the other day about safety, and one of the things we talked about is how to make a safety plan, creating a safety plan. If you know what medications you take or treatments you need, you need to know those things so that if you have to leave quickly, or because of COVID, you're going to have to hunt-- things are going to close down, you need to know what information and medicines and things like that. If you can't respond, someone will have a list of your medications or something like that.

>> What advice would you have for people with disabilities to know what's in their record to really own their health record?

>> The number one advice I would give is to ask questions, and don't stop asking questions until you're satisfied, and understand the answer. If the first person won't explain it to you, ask someone else. I have changed doctors many of times because I was not pleased with the care I was getting.

Sometimes the first doctor might not work for you. I tell them, in order to own your health, you have to understand your health. In order to understand, you must ask questions. You are not a doctor. You might be an expert on your disability, but they aren't experts in the field of medicine.

Ask those questions and talk to other, not just necessarily doctors, maybe you can talk to social workers or nurses or advocates, different types of people who might not be what you would consider traditional health professionals but might know enough about healthcare.

I talk a lot of time to my pharmacist. My pharmacist helps me understand a lot about why medicine this or what I need to do for this. Pulling on those different supports is huge and asking questions and not being afraid to ask those questions and try to get as much clarity as possible and writing those questions down. Getting the clarity you need and knowing exactly what to ask or say, I really don't know what it's called, but this is what I want to know. That's my advice to people.

>> Yes, just keep asking the questions. That's great. That's great advice. Sherice, one of the other things that this Twitter chat percolated, mentioned was the idea of going through your health record at least once a year to know what it says, what's in there about you, because it's your body, it's your health. What may be some ways that people with disabilities might take action on that?

>> I would venture to say you should do it every six months actually.

>> Oh, raising the ante.

>> Yes. Let me tell you because if you're taking medications, your body is ever-changing. The environment is ever-changing. Different medications are always becoming available, different treatment options. You need to keep as much of a detailed information about what medicines you're taking, how it is affecting you. If you want to get really fancy, keep a diary. Every few months when I go to my doctor. I tell them, "Listen, this is the medicines I'm taking. Are they all still necessary?"

It could have been I went in and took blood work, and my cholesterol was out of control, so he put me on cholesterol medicine. "Can you check my cholesterol again? Is it still out of control?" I have high blood pressure. Is all of these medicines still necessary? Is there something where I can lower the amount of pills I'm taking to something more tighter, less invasive? Is this still least invasive thing you can give me?

Having those conversations, I tell them it's important to them every six months to a year because you never know what's now available because sometimes your doctor is seeing so many patients, they might not know to tell-- They could tell you, or if they've told you if something that was available.

For instance, I go to a neurologist for migraines, and she's always up on new stuff that's available in terms of treatment options. She's always tweaking my medicines. She says, "Okay, this is a better option for you," and I see her every six months on the diet. It's to make sure you're getting the best treatment possible, the best medication possible, the best information because medicine's always changing. That's my suggestion.

>> That's great. Sherice, thank you. It goes back to knowing what's in your health record and owning it. That's a great summary from what we heard in the Twitter chat and the themes around that. Just to review, ask questions, and don't stop until you're satisfied and you really understand. Get support, get an advocate, whoever that might be for you. It might be a nurse in the practice. It might be a trusted family member. It might be a social worker but get an advocate locally that you can trust and who knows you and can walk through what's in there.

I love that you said, Sherice, yes, maybe every six months is better than once a year, but at least know what's in there. Know what's in there, know your health record.

>> I would encourage healthcare providers to put it in plainer language. We know you have to have some technical terms in terms of what a disability is called, but know that you're not dealing with people who've been to medical school or have medical training, and put it in the language and the format that they can access because not everybody has internet access in rural Arkansas to be able to go on a portal to get access to their health records.

>> Then that goes back to the assumptions and not making so many assumptions with all of this as you were saying.

>> Right, absolutely. Those are just some of my suggestions and thoughts of what I think are so important. I am sure I'm missing something, but those are big ticket items.

>> You got the highlights. I think you got the highlights there, so thank you. Was there anything else that you wanted to add or anything else that you heard from the Twitter chat that you would want people with disabilities or health care providers to be thinking about?

>> I think the one thing I heard, and I can't remember who it was from or the exact context, but it reminded me that your health records are not just a piece of paper or a form. There are other abstract things that are involved in only your health records, whether it's transportation, whether it's access to the internet, access to different services, advocacy. Those are all that will help you own your health records.

If I don't get access to the internet, how am I going to get my health records if it's on a portal? If I don't have transportation to quality health care, how am I going to be able to take my health care provider to get someone who's willing to assist me in understanding my health records? I think we have to think a little outside of the box with owning our health records. That would be what I would leave you with.

>> That's wonderful. Yes, be creative, keep thinking about all the ways that you need support to really own your health record. Great. Well, thank you, Sherice. I know we're at time for the interview. We wanted to make this under half an hour, so, folks, log on and listen to it. I want to thank you for joining us today and thank the interpreter for working with us today. We want to make sure that everything we share out from AUCD is fully accessible. Thank you, Sherice, for taking part today in the interview and for being one of our discussants during the Twitter chat on Own Your Health Record.

>> Thank you so much for asking me and having me. Thank you.

>> Absolutely. Thank you.