

AUCD – Taking Charge of My Health  
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Remote CART Captioning

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Donna CART Captioner: Please stand by for captions.

>> Hello and welcome to Taking Charge of My Health Care. A toolkit by and for self-advocates. I would like to thank you all for joining us today. I would like to address a few logistical details. Because of number of participants, audio line is muted throughout presentations. At the end, you can submit questions during any time of presentation. We will compile your questions throughout the webinar and address them at end. We may not be able to address every question. This webinar is recorded and will be available on AUCD webinar library. We invite you to provide feedback on webinar and provide suggestions for future topics. I will turn the mic over to Lindsay Sauve who will start us off.

>> Thank you, Anna. And thank you to all of you who have logged in this morning or this afternoon depending on where you are. We are really excited to share this work and toolkit with you. It's been a project that we have been working on for a few years. Collaborative project with several organizations here in Oregon. It's self-advocate driven and created and also now disseminated. We are thrilled and proud of this work. Thank you for joining us.

>> My name is Lindsay Sauve. I am program and evaluation manager for UCEDD at University Center of Excellence on Developmental Disabilities. Michael Steen is here with member of OSAC.

>> Erin Taylor. She is health promotion and outreach coordinator. She worked for OODH and UCEDD. We are all sharing a computer and all sharing a headset. As we transition presenters, there maybe a 30 to 45 second delay while we pass the driver seat to next person. FYI on that. Today, just to go over our agenda today. I will talk to you about history of Taking Charge of My Health Care and how developed and Michael will talk about importance of advocating for one's healthcare and how this is important resource. Erin will walk you through the toolkit on the website. You will see the component and learn about different tools available. I will wrap up by sharing ideas about how all of you could utilize the toolkit and different settings where you work and the different communities that you are in.

That's what we are going to be talking -- we will have some time hopefully at ten or 15 minutes at end for Q&A as well.

Just to share with you a brief overview of project history and how this came about. April 2016 that is three years ago. OSAC approached the UCEDD and OODH. Self-advocates need better way to advocate for healthcare. We provided this toolkit. In our community and hopefully beneficial for Self-advocates across the country. We have been able

to find templates from Australia health department. They gave us permission to use templates for our version. We didn't have to recreate the wheel. We acknowledged Australia health department for those templates. We had lots of collaboration from Self-advocates. Really Self-advocates telling our offices what they wanted, how this information could be helpful. How to tweak this information to be more accessible. There was a lot of collaboration over that year.

We also developed an expert panel media up of self-advocates, healthcare professionals and parent and say others. Once we had the final draft of these documents and pieces, we had a panel review and provide further feedback. We started then planning for production of developing videos for each of our modules. We are not going to be able to show you those videos today because videos don't really show very well over webinars. We are going to show you how to access those. We will tell you how those videos are created. They are an important piece of this toolkit. They are designed and developed by and for self-advocates. We will talk about that in the webinar. We did 84 hours of filming to create these videos and presenting at the OSAC's board meeting. We developed a website to host the toolkit and we have a way to disseminate the toolkit and talk to them how to use this information to support self-advocates they are working with and presenting to self-advocates as well.

I think at this point, I'm going to turn the mic over to Michael who is going to talk to you about the importance of advocating for one's own healthcare.

>> Okay. Good morning, everyone. My name is Michael Steen and I'm going to make a few comments about -- make a few comments about distinct importance of being a good self-advocates. I will first say that it definitely encourages that curriculum is able to take ownership of their own healthcare decisions and also make good on your own action.

My opinion for your overall (Indiscernible) as whole, we need to develop the buy-in from the patient so that he or she will be able to develop a better sense of understanding of their responsibilities in the overall healthcare component of their lives.

Further, I will say that it is very important that the primary care provider will be able to develop a more well-informed understanding of the unique physical and parts for mental health issues that the patient may have. With that said, through an understanding of influencing factors affecting the patient's health, the PCP will then have a holistic understanding for how to best meet the needs of the patient.

Finally, I will say that one of the key reasons for being a self-advocates between the self-advocates and the (Indiscernible) is that basically that will allow for a more trusting relationship to develop so that both the patient and the doctor will have sort of both the patient and the doctor will be able to develop a fairly of a mutual respect for one another.

Thank you. Now I will transition over to the importance factors of -- of healthy lifestyle choices. Just like in general for overall population the choices that we make in our day-to-day interaction has a profound impact on the well-being -- overall well-being. I have been able to emphasize a plant-based whole foods diet by being careful to have real balanced protein and essential nutrient mix so that I'm healthy from nutrition standpoint as possible.

Second exercise, I find that because I'm able to structure my day so that on day-to-day basis, I tend to be more -- I tend to try to structure my day so that I have opportunities to build an active lifestyle such as, for example, being able to take a walk if it's only about a half-mile commute versus trying to ask someone for a ride or else taking a bus.

>> Thirdly, I would say the mental health component is also equally essential as we all know. That works for me by being able to maintain community involvement with a variety of groups,

spending time with friends while ours are balancing out with some time for myself to meditate or simply enjoy a nice walk in the park. Lastly because none of this happens in a vacuum, it's important to have strong support of friends and healthcare professionals and providers to be able to turn the decisions we make into the actions in our day-to-day lives over the long term. Thank you.

>> Next, we are going to hear from Erin Taylor. Erin is going to walk us through the healthy or the taking charge -- Taking Charge of My Health Care on the Oregon Office of Disability website. We are going to share our screen. That's not what I meant to do. Give me one second here. Share my screen. If those of you are interested on looking at this on your own, the website is [www.ohsu.edu/oodh](http://www.ohsu.edu/oodh). If you drop down to health promotion tab, will be under that tab. Erin is going to walk us through and show us what this toolkit entails.

>> Good morning, everyone this thank you for joining us. You can go to the website of OHSU. You can go to health promotions here and this is down at bottom. For easy access, we have a button down here where you can push view toolkit. This is giving you overview what Taking Charge of My Health Care Taking Charge of My Health Care as far as health and access for people with disabilities. Talks about how it came to be about and different topics that we have for fact sheets which I will get to into few minutes. We have testimonial hear. I love this from OSAC disability members. The toolkit being offered in video and written format helps get the message across to everyone. When we talked to those members, that is something important not only having the modules but the videos. To be able to allowed more access to everyone. If we go to the toolkit. I will walk you through how this goes. Our internet is slow today too. I'm going to talk about it while it actually comes up. Designed to provide self-advocates with tools and how to best advocate for healthcare. Modules from Australia, seven of them. We sandwiched them with being a self-advocates. It's important to know what a self-advocate is. What does that take to be a self-advocate is important to know. Our first module that see to do with being a self-advocate. Michael shared this so nicely, importance of holistic health and how he does that through diet and exercise and social connection and time for mindfulness and medication. We decided that having a module 9 for staying healthy to be able to show that in between doctor's appointments, you don't want to have that relationship when sick. You want to have ways to stay healthy and keep your overall wellness good in between those visits.

I'm going to move back up and show you what we have. In the toolkit, you can see each one has video. We have modules here and we have a worksheet and we have a PowerPoint and another way you can get to the video. I want to scroll down and go over that one to show you. This shows a lot about collaboration how we were able to come back and come up with some really good points for me and my medication.

If you click on module for each of them, we have me and my medication. This is the fifth module. All of the modules have same format. First page says you can find and has each section. As you scroll through the module, you can see each one understanding my medication. This aligned with five or how many topics each module has, they have a different amount. When we took this module to OSAC. We have a topic like medication safety remembering. Important to follow and be safe while taking medication. We don't have any way to -- tips to remind us. We got on a whiteboard, tell us ways you remember to make your medications. Be sure to take your medications at same time every day. Turn your bottle upside down. Count your pills. Have someone remind you. Use a pillbox. You can sign up for a text, call or e-mail reminder service.

There was a lot of collaboration in remembering helping us to where we could all collaborate and be able to come up with module that encompassed everything that was important for them in self-advocacy. As we get through last section, what did I learn, I can take a charge of my healthcare when I. You have which ones and what main points of each module is. And then a note section. I'm going to go back now and show you the worksheets. Along with module, we have funding worksheet for each module.

Waiting for that to come up. You can see on here, we have a word banks and how to fill out words. Each has different type of structure with it and message to it. Different tips to help you to remind you to take it and what to do if having a medical emergency. Most of worksheets are one to two-pages depending on length of module or content. Got to get back in there. As far as the content.

We also have if we are doing -- if we decide to do worksheet and don't have access to videos, we have PowerPoints also. Let me scroll down. PowerPoints have the main points that all of the videos do and the modules. They are just in another format to be able to show it. I'm going to see if it will pull up. Here. We use the same images and has different questions in the PowerPoint. If you want to facilitate with group, you can do that as well. We have that to go along with each -- for each module.

And then so that is basically our website that we have. So when I go back to the -- I'm switching over screens real quick -- there we go. Give me just a minute. We're trying to get back to the PowerPoint real quick. Here we go. Yep. So I just want to go over real quickly all the topics. We have being a self-advocate. Me and my doctor. Me and my medications. Signs of sickness. When my doctor recommends surgery. Mental health and staying healthy. I want to say where mental health, this is important one for OSAC members. They wanted to be actors in this one and have input. They really wanted to have a module that would help break the stigma of mental health. That's okay to talk about. Video talks a lot about that. We have a page that talks about how to break the stigma of mental health. Really important to be able to talk about it. That was a meaningful money for everybody that we worked hard -- we worked hard on all of them. That one had a special place. Other thing we are going to be adding to toolkit is leaders guide. We have to get a couple of pilots ran before we can put it up on the website. Leader guide is going to be for self-advocate trainers. I or Michael or Lindsay would be able to go to the workshop for taking care of my healthcare to be able to show somehow to be used. They have instruction how to do workshop and ideas for activities to facility discussions. They thought it would be good if working on healthcare that would be nice to add scenarios for each model. When in the process of doing a workshop. You can talk to new doctor to see if they are a good fit. One of modules that my doctor recommends surgery, surgery is scary for anybody. Would be able to give us a chance to what type of questions you need to ask. Gives us that chance to be able to in a small group where it's safe to role play and practice those things out. That's going to be interactive part. We are going to have different fact sheets. On various health on topics from intellectual developmental disabilities and resources. Such topics such as how to best understand were communicate with a person. We have ones on sexual health. We have one on contraception. There is one for dental health. One for mental health rights. And like your rights as a patients. We are hoping that these will be a good healthcare resource for parents and disability service providers. I was presenting to nurse practitioners, how nice it would be to have these to pass out or few minutes that patient had in the room to play one of the videos. Nice to be able to see how not only in a workshop setting but how other people and

nurse-practitioners and healthcare providers thought this could be utilized in their office itself. These fact sheets, we are hoping to have them out by fall. We want to make sure that they are accurate and easy to read. That pretty much, we are going to have a site on the website of supplemental information and handouts too that we have gotten from various places. Different tool -- different like doctor summary orders that you -- visits you may want to use to be able to fill out for doctor's appointments. We have different pain charts and different supplemental handouts that you will be able to access. Everything you can download and completely free. There is no cost. Which we know oftentimes that is a barrier. We do not want that to be a barrier. You can download it at any point on OODH website. I'm going to pass this over to Michael now to talk about the videos.

>> I will make a few comments about the experience we are as actors in regards to all components on making the videos you have seen or you will hopefully see eventually. 25 people participated in the production of the videos. Roughly ten self-advocates and rest were healthcare professionals, students, et cetera, that -- spend some time with us. Videos were done over two days. First day, I would say on overview while basically through the staff -- through the staff between OSAC and also up here -- read through the script following through variety of healthcare related self-advocacy topics. Videos by professional third party consultant. That took -- so basically with that said, that took few days of on site filming at location up here. And then a few weeks later, we went to off-site location making use of motel suite to be able to say as if we had what it would look like in the field for actually being able to implement the healthcare happened book in real time -- handbook in real time.

For myself, you will see that I was part of -- me and my doctor. For then scene, we made use of a hospital room and there was a very kind doctor in need of -- who knows. Who was able to play act with us. Various components of in my case what it would look like when I'm actually being examined by a doctor (Indiscernible) that would be more appropriate for me to ask so that I can have a meaningful dialogue and more importantly able to leave that environment with that, so written down the information that with actually written down information that I could refer to at a later time.

Overall, I would say that it was definitely a very enjoyable experience that we were proud to be able to see. We were all proud to add our component to it. Go off script will appropriate and be able to have a little fun with this.

We -- with that said, we hope that you enjoy seeing the videos. Thank you.

>> Thanks, Michael. So one thing that we forgot to mention about the toolkit is that we are slowly having each of those components translated into Spanish. First component of toolkit that will receive Spanish translation is the videos and closed captioning. I'm not sure if we have -- sounding like ends of June we would have Spanish versions of the videos available. And, yeah, we will work on translating as we get funding the toolkits as well and the Spanish. I think we are ahead of schedule here. Anna, I just got your note to enlarge, sorry about that. So just kind of thinking, you know, how can this toolkit can be used, what settings, who is the audience we have a few ideas how this toolkit could be used by the community. Each module does have a PowerPoint available to it and working on developing a leader's guide. Each of the modules could be presented as workshops and, you know, day programs or in residential facilities or we're hoping that to have a peer facilitator to that training. These are workshops that are presented by self-advocates for self-advocates. There is the option of using this toolkit one on one. If you support individuals with -- or a healthcare provider who wants to work with your patient on taking charge of different components of their healthcare, could definitely by

used one-on-one. If you have access to website, you can go to the toolkit, watch a video together. Watch a module together. Doesn't have to be presented all at once. There is different components of this toolkit that could be relevant to particular situation. There is a module about mental health. If you are working with an individual who is having some challenges around mental health or maybe has a history of mental health needs and would like to build skills around kind of recognizing their mental health and being proactive about their mental health, this would be a great opportunity to sit down and go through the video and go through some of these modules and learn and build skills. Definitely one on one.

Learning healthcare skills, being proactive about one's own healthcare is great thing to put in IEP or ISP. I think particularly thinking about transition and folks transitioning from childhood to adulthood, when they transition from pediatric care to adult care, there is the dropoff in them having access to care. There can be issues with if they don't have parents there to go with him to go to the doctors, skill building to help them transition into the adult healthcare world taking on their own insurance and managing those kinds of things. Definitely can be worked in IEP or ISP. Parents could benefit from reviewing this toolkit and understanding the different components of health that their child might want to start taking on themselves. You know, depending on the individual, you know, 12, 13, 14 might be a good age for youth to start making their own doctor's appointments or going on their own or rather than with the patients. And this could be a great way for parents to work with child to build some of those skills. Definitely sharing this with advocacy groups. Self-advocacy groups. They can share that with self-advocates and their communities. We know that there are a lot of healthcare providers like nurse practitioners and therapists and physical therapists. We could see the use of doctors and healthcare providers knowing this toolkit. If they are working with patients that need support around understanding medication or maybe needing to have a surgery. Particular module about surgery. This would be a great opportunity for provider for healthcare provider to say, hey, here is this module to learn what surgery is all about. And kind of, you know, advocate for yourself and have skills what that is going to look like and what that experience is going to be like for you.

Lots of different opportunities to share this toolkit. Just thinking about next steps. We are not done. We are proud of what we have put together and we are still working on it. As Erin mentioned, we are working on developing and disseminating a leader's guide. Leader's guide again is a facilitator's guide for workshops that can be done around these modules or toolkit. These would be workshops designed to be peer facilitated. Working with self-advocates to conduct these trainings. We are going to likely be finishing up that leader's guide this summer and piloting a few workshops around Oregon.

We are going to be testing that out and seeing how that works. We visited several rural communities in Oregon. Shared the toolkit with communities and got feedback how can be disseminated and next step is to go out to rural community and say do pilot workshops and shared it around the Portland areas and our area as well. Developing and disseminating the fact sheet. These are resources for parents and support providers. And, again, 19 different topics related to health and with the lens of being able to provide that support for somebody and how to best provide support and information around these different health topics. Then I already mentioned we are going to be conducting pilot trainings around Oregon and OSAC members. Amazing to me how involved OSAC members have been and willing to be involved and every aspect about this. Not just about the development of this toolkit and filming of videos. Now that we have this toolkit together, we had an OSAC member at every member we

disseminated at. We have gone to communities around Oregon and shared this and been able to bring an OSAC member to share the importance of this toolkit and how can help people which has been incredible. We really -- yeah, this toolkit would not exist for our OSAC.

All right. So, we kind of sped through that. We do have definitely plenty of time for some questions. So I'm going to -- oh, let me just say that this last page here, sounds like Anna is going to be able to e-mail out the slides. This first website here on Oregon Office of Disability, that's where you access the website. You click that health promotion charge. It's right there. I encourage all of you to spend time on it. Watch those videos. We couldn't show the videos over the webinars. Never works well to show them. Take your time to watch those. Those are three to four minutes each. They are well done and they are a great resource for any folks who need to kind of learn and build skills around taking charge of one's healthcare and being healthy and going to the doctor and those things. And then our contact information down there at bottom. If you would like to reach out to any one of us, please feel free. We will answer questions and share more information about this project.

>> I think that's it.

>> Thank you, everyone. We have time to ask questions. You can ask questions in the chat box. We have a couple I will read after I'm finished. If you want to ask on the microphone, I will un-mute you. Or on the phone press star pound and that will un-mute you. Was any work done on putting advance directives in place?

>> That is a wonderful question. I don't know. I'm going to turn over to my co-presenters. Do you know if anyone talk about advanced directives.

>> That is something that has been mentioned advanced directives and when the age of transition age of when they have their own rights as an adult. Those are both things been brought up. We are keeping a list of different topics like this and possibly doing a 2.0 that OSAC members are all on board. These nine modules is what we came up with. Hearing that as a question, kind of brings to light that that is a topic that needs to be discussed.

That is one of the topics we are looking at doing a module in the future.

>> Other question we have is from my colleague. Past health -- healthy lifestyles have required facilitators to attend training to familiarize themselves with the materials. It appears that this material is open source. What steps are you taking to ensure that facilitators and trainers are adequately prepared to teach the material?

>> The Oregon Department of Health is home organization of healthy lifestyles. Yes, there is talk about that. I think one of the comments that I have about that, I don't know that we really talked a lot about that. About whether it's going to be whether the facilitators guide is something you need to be trained in. Will people need to be trained in this curriculum in order to present in it? I think we are thinking no. One of the reasons -- part of it might depend on whether we evaluate it. At this point, it's not. It's a resource for the community. Communities can adapt and use it. We are not concerned about fidelity in this training. Keeping with that open source. People can use however they want to. Resource to have conversations.

PowerPoints and facilitators guide, they are not deep curricula, they are disseminating information and using toolkit. I will say things develop and conversations about whether we will see this -- see this as a curriculum and see this as an intervention and want to evaluate it and talk about fidelity. We are not seeing it that way. We are seeing it as a resource that people can adapt. Hopefully that answers your question.

>> Okay. We have another question. Does concept of shared decision making supported decision making get covered in any of the module as well as possible need for health

surrogate?

>> That's a great question. We talk a lot about support shared decision making. And I think that -- and I might turn this over to Erin or Michael to -- I don't want to be the only one who is answering the questions. I think that supported decision making is underlying theme throughout this toolkit. Self-advocates are very much about turning the tied around being apart of the decision -- a part of the decision making around healthcare. That is the reason for this toolkit is to provide self-advocates with schools and resources to make decisions on their own. As you go through and read the videos. We don't call out supported decision making in the modules. We don't say the words supported decision making, it's an underlying theme that this is to support people and work with people who support them and empower the people who support them to allow or support -- to provide that supported decision making so that not only do the -- they have information to make the decisions. They have skills to provide support in that way.

I will turn it over to Erin real quick too.

>> I would like to add to that as well. We do have throughout the modules, we have to where a support person is mentioned. Being able to have that as a part of advocacy, saying, I have the person in the room with me to support or write notes or making sure that understanding or everything is being understood in the office and for the visits.

We have in module two, I believe, for a person centered. So finding a doctor who has person centered philosophy. We try to embed throughout ought of it whether -- all of it whether to have a support person with you, we have embedded throughout all modules. That is important for members to know. Sometimes advocating for your healthcare is making sure that you have someone else in the room with you to help support you.

I hope that answers the question. Do you want to add anything?

>> Just a second, Michael has something to add.

>> Thank you, yes. One component I would add is that our view with this various module to be able to present the essential -- docs that both the individual experiencing IDD would know in very colorful (Indiscernible) as well as for the primary care provider to have that understanding of, okay, basically understanding that these are skills that my patient is now familiar with. So basically, the doctor will be able to have a more meaningful conversation because he or she will trust the patient.

So just to reinforce, I think using these as essential level -- kind of allows the individual to then be more comfortable talking with those in the network, being able to facilitate that conversation. Thank you.

>> Thanks, Michael. Next question.

>> Sure. Is there a way to be informed of when the training on how to start your own workshop using a toolkit as a guy will be available? When will the training be available?

>> Being informed when we are putting that together. One option would be to sign up for the Oregon Office of Disability and health news letter. Once we have that launched, we will be announcing that on newsletter. You can e-mail Erin or I. You can go to the Oregon Office of Disability home page. I think there is a link to sign up for newsletter. We will be announcing that when that happens. That will be July or end of summer. Will be after our pilots. We will be doing pilots like fall or winter of this coming year and then after that, probably midwinter, I'm going to say like January or February maybe next year after piloted the workshops and gotten feedback and adapted the facilitators guide. That's a loose timeline.

>> Next question?

>> Yep.

>> Do you plan on including anything on sexual and reproductive healthcare topics?

>> Thank you for that question. I know that the sexual and reproductive healthcare topics will be in the fact sheets. I'm going to turn the mic over to Erin and have her comment on that.

>> So this is another topic that comes up an awful lot as well as advanced directives that were mentioned earlier. We are keeping a list and for OSAC members they want to address sexual health and reproduction. We are looking at doing that down the line. We have that as Lindsay says in the fact sheets. It's briefly in module 9 now. Just mention as far as ways to stay healthy. And, yeah, for checkups and different things like that and how to like maintain the good health. Different types of checkups to have. One thing I will say, we media these modules where they are gender neutral. With leader's guide how that is set up, it's modules with brainstorm questions to help facilitate conversation and get people talking about the different questions and aspects of healthcare. As far as the -- it's the modules with questions embedded in the modules as well as we will have the scenarios for the role playing and then different ways we will have in there different ways that you might be able to use the health the toolkit, the leaders guide actually, different ways to use it. That's why it's free form and able to tailor it to your personal needs. Sexual health is definitely a topic that our office is very passionate about. That's one of the pain point that is we do want to add when we do to add extra modules.

>> How will you choose the pilot participants. Will you be in central Oregon to do any pilots?

>> We did dissemination of this toolkit this year and Bend is one of communities where we held community to have toolkits. There is a plan to go to Bend to do one of the pilots. Thanks for asking. We hope to see you there.

>> We have a couple of comments. Congratulations on great toolkit you created. Amazing work from Kathy. And thank you for sharing this valuable resource to facilitate healthy initiatives in the community we serve.

>> Those of you who do end occupy using this -- end up using this, we would love to hear how you used it. Any kind of feedback that you have, you have our e-mail addresses. If you do use it, we would love to hear how it's actually being used by folks.

>> Thank you.

>> A little trigger happy.

>> And Jennifer asked, when you come to Bend how will we know you are here? Will this be in your newsletter?

>> We are hoping it will be. We can make sure that you are on our distribution list. We did advertising through service agencies, brokerages, county, DD services. Those folks. If we are missing anybody, we love to get healthcare providers at these trainings as well. If we are missing anybody through our distribution lists, shoot us an e-mail.

>> I'm going to give it a second for anymore questions.

Check the phone lines and so there are no more questions. So I would like to thanking our present -- thank our presenters for awesome presentation. I would like to thank everyone for attending this webinar. This has been recorded and will be at library at [aucd.org](http://aucd.org). If should be there by end of day tomorrow. If not, bug me, it should be there. Under resources. If you would like any more information about this webinar, contact information is right in front of you. I pulled up the screen. If you can take a few minutes to complete our survey when we close out, should pop up on your web browser, that would be awesome. Thanks, again, everyone and have a great rest of your Tuesday.

>> Thank you, Anna. Thanks, everyone.

Donna CART Captioner: Meeting has concluded. Thank you.