

Self-Advocacy Online & Research Translation Presentation Transcript
August 29, 2013, 3:00pm-4:00pm ET

Please stand by for real-time captions.

Hello and welcome to the webinar. My name is Anna Costalas and I am the AIDD Technical Assistance Program Specialist at the Association of University Centers on Disabilities. This webinar will address Self-Advocacy Online & Research Translation: Fuller Participation for Individuals with ID/DD. This webinar is presented by AUCD's National Community Education Directors' Council, and is supported by the Administration on Intellectual and Developmental Disabilities through the UCEDD Resource Center.

Before we begin I would like to address a few logistical details. First, we will provide a brief introduction of our speakers. Following the speaker's presentations there will be time for questions.

Because of the number of participants, your telephone lines will be muted throughout the call. However, we will unmute your phones one at a time during the Q&A time at the end; you will need to press *then # on your phone to request to be unmuted to ask your questions. You can also submit questions at any point during the presentations via the chat box on your webinar console. You may send a chat to the whole audience or to the presenters only. We will compile your questions throughout the webinar and address them at the end. Please note that we may not be able to address every question, and may combine some questions.

This entire webinar is being recorded and will be available on AUCD's website following this webinar.

There will also be a short 5 question evaluation survey at the close of the webinar. We invite you to provide feedback on the webinar and also to provide suggestions for future topics.

I will now turn the mike over to Amy Sharp, Chair of AUCD's National Community Education Directors' Council who will introduce our speakers.

(Amy Sharp) Thank you for attending this great webinar. This webinar is brought to you by the National Community Education Directors' Council which we call and NCEDC is a core function of University Centers for Excellence in Developmental Disabilities (UCEDDs). NCEDC offers community service activities that include community education and technical assistance for or with individuals with developmental disabilities, their family members, professionals, paraprofessionals, students and volunteers. Our mission is to serve as a forum to discuss best practices about information dissemination, community education, and technical assistance. We also serve as the voice for these issues within the UCCD network. We invite you to join the

NCEDC listserv to stay informed on these activities. If you want to know more about us I just posted our contact information and the chat and you can contact me there. I want to share in October we will have another webinar on collaboration between core functions doing more with less. If you are interested in that stay tuned and information will be available. For today we will talk about self-advocacy online. This is an educational and networking website for teens and adults with intellectual and development of disabilities. Key areas are self-advocacy groups, video story wall an online learning center and research that are translated to accessible documents. Our speakers today are John Smith, he is a project coordinator and researcher at the Research & Training Center on Community Living and Mark Olson is a project coordinator for NIDRR at the same center where he writes curriculum and provides training to people who provide direct support. Hunter Sargent will be joining us and he is a Native American, songwriter, and self-advocate. He is also a dynamic public speaker and advocate for others and he works with our and people first groups in Minnesota and I will turn it over to our speakers. Thank you.

(Mark Olson) Hello and welcome to the webinar on Self-Advocacy Online. It is an informational website for teens and adults with intellectual and developmental disabilities. I am Mark Olson and John Smith and Hunter Sargent will be presenting with me today.

The idea for this website evolved here at RTC over the past 10 years as our experience with the web and media technologies increasingly intersected with our research and dissemination activities. Recently we joined The Arc of the United States to promote this website nationally.

(Mark Olson) A decade ago, most information about self-advocacy was not easily accessible to self-advocates. Much of it was in three-ring binders and not easily used, or it was in the possession of only certain groups.

(Hunter Sargent) As a public speaker on FASD and self-advocacy, I need good tools. The Internet really helps me reach a lot of people. And as a self-advocate this website has been great, giving me access to good information and other opinions.

(Mark Olson) The Internet has certainly made it easier to share information. However, the process of making information accessible – translating knowledge into usable, concrete information, take a lot of work.

(John Smith) Development of Self-Advocacy Online evolved from lessons learned on other projects at the Research and Training Center on Community Living – the College of Direct Support and Quality Mall. Through these projects we developed considerable expertise in curriculum design, web development, media production, and content delivery. With these and other projects, however, we felt we were not addressing the learning a style of many self-advocates. With initial support from the NEC Foundation and later a grant from the MacArthur Foundation, we were able to build Self-Advocacy

Online.

(Hunter Sargent) Today we are going to provide an overview of the website and cover the four key areas: 1) Finding and listing self-advocacy groups 2) two, a video story wall 3) a learning center on important topics in self-advocacy and 4) accessible research studies.

(John Smith) Let's visit the website ... On the homepage - <http://www.selfadvocacyonline.org/> you'll see news entries about events happening in self-advocacy, along with updates made to the website. For example, here's a link to highlights from the recent Arc national conference in Seattle, which included a large self-advocacy pre-conference.
http://www.selfadvocacyonline.org/video/Arc_2013_wrap_up_BEST-medium.mp4

(Mark Olson) At the top of the screen we will find buttons for the four key areas of the site. As you can see here, these four are the key areas. Here on the first one we can find Self-Advocacy groups around the nation. You can go to a state and look at the state by clicking on the state itself, or if you would rather use a drop-down menu or zip code, you can look for them that way. We will click on New York and it will show you that we have a number of different self-advocacy groups that are listed in New York. One of the things we like to mention on here is that this is a work in progress and also one of those pieces where we need a lot of people to help us make sure that the information is up to date and actually if you go back the information tab, you click on that and have the opportunity then to insert the information for any self-advocacy groups you are involved with. Obviously, we love to have self-advocates that are doing it, but if support is needed, make sure the information is in there so people in your area can actually get to the Self-Advocacy organizations nearest them or if they would like to be a part of.

(John Smith) On the "map" screen (<http://www.selfadvocacyonline.org/find/>) you can add or edit your group's information. Group information can go out of date quickly so we need groups to use this form and keep their information current.

(Mark Olson) Another key area that we have on the site is Self-Advocacy stories - <http://www.selfadvocacyonline.org/stories/>. We have a number of stories on here that -- I will let Hunter tell you more about this.

(Hunter Sargent) Let's take a look at a few of these stories. The first video is about bullying. This is a topic I'm very passionate about. In fact, I recently recorded a rap about bullying and we're working on a music video that we'll post here on Self-Advocacy Online.

(Video Caption) "When I was in school, I was known as very passive. It was easy to take advantage of me and be bullied. I was a target of being bullied. It was bad. Where I was tripped, harassed being threatened to get beat up. I was called the F word and R word. That was very hurtful. I remember going home sobbing. It was so hurtful. People

need to stop and think before they say something hurtful. My advice to people out there, who get called names, is to speak up for yourself. Tell them how it makes you feel.”

Let's take a look at a self-advocate talking about how she feels about the R word.

(Video Caption) “They made me feel like I want to say uncomfortable. And it made me feel like I was lower and less than and it made me feel like I was not compatible with what other people could do or understand what exactly was going on. Sometimes it made me feel like stupid and dumb. “

Let's look at one more story. This one is about community inclusion.

(Video Caption) “I think that self-advocates biggest thing is being included in the community and with society. And inclusion within college, schools. Letting someone be there. Not saying they have to be separate. Allowing them to be exposed within regular people and loving people for people. I don't care what the scenario is you have to embrace people and love them no matter what.”

(John Smith) We're heard from groups that are using the story wall in self-advocacy trainings, choosing stories based on certain topics. As we add more videos to the site we'll create an easy way to search for stories based on keywords.

(Mark Olson) The third key area of Self-Advocacy Online is the learning center - <http://www.selfadvocacyonline.org/learning/> , featuring accessible lessons on key topics in self-advocacy. We recently created new lessons in partnership with The Arc's HealthMeet project. Let's look at a few screens from the lesson on exercising. You can navigate through the screens in order by clicking on the red arrow, or you can select screens by number. Let's jump to screen 11 for a workout. Feel free to join in on this cardio workout! <http://www.selfadvocacyonline.org/learning/exercise/>

(Video Caption) “In this lesson you will learn about exercise and moving your body. Learn about different kinds of exercise. How much you should be getting each week and how to fit it into your busy schedule. Click on the arrow to begin. It is important for your health to exercise and move your body. Let's learn about different ways to exercise. Click on the arrows to begin.” As you can see, it has a nice arrow telling you where it is. In that piece you can navigate that one. The other possible navigation method is to navigate my screen. And going up to the screen and looking at -- Cardiovascular exercise or cardio get your heart pumping. With cardio, you breathe harder. Let's look at the two kinds of cardio exercise. Let's do some moderate cardiovascular exercises. Click on the video link to do a two-minute cardio exercise from your chair. “

(Mark Olson) I will click on this for a while and you can maybe do some cardio here with us. It has been a long day, sure for everyone.

(Video Caption) “Do what you can. Before we begin, you are probably reading easily, slowly. Now feel your heart rate right touching two fingers on the inside of your wrist. Your heart is probably beating steady and slow. Let's get started. Roll your shoulders forward in small circles.”

As you see we embed videos and use other pieces and draw from other resources to make the lessons, life. -- Make the lessons come alive. Hunter?

(Hunter Sargent) If you'd like to take a rest from all of that exercise, let's take a look at the lesson on Speaking Up for yourself. Pay special attention to the golden voice of the narrator. This lesson is about the first and most important -- important part about Self-Advocacy, learning to speak of yourself and others.

(Video Caption) Self-advocacy is about taking responsibility. It's about having control over than positions that affect your life and about being in the driver seat of your life. Steering in the direction you want to go. Sometimes it seems impossible to be in the driver seat. How do you learn to get control of your life? The first step is learning to speak up for yourself. It is pretty simple and it is one of the most important skills to learn in life.”

(Mark Olson) We are in development of new lessons in areas of health, personal safety, voting, bullying, and leadership. This process takes time as the content goes through a lengthy process of editing and review. A team of self-advocates meets monthly to review the materials and they have input at multiple stages of the process so that we are sure that what we are producing is meeting with self-advocates are saying that they want and need. This leads us to the final tab we have on the page and that is our research for all tab -<http://www.selfadvocacyonline.org/research/> . The mission of our website is making current topics in self-advocacy accessible to people with intellectual and developmental disabilities it is applied here to important research. Scholarly articles are often difficult to understand, but it doesn't have to be that way. We've identified current research findings that are important to self-advocates' and translated them into accessible, useful documents, using narration, data *visualization*, and *clear and simple language*. *Let's take a look at this research* translation asking if people with disabilities get the help they need.

(Video Caption) “Do you live a good life in the community? Do you get the help you need? Does your family get the help it needs? It is sometimes hard to find support services. We want to know if people with disabilities are getting the help they need. Scroll down to learn more.” And then we scroll to the next section and we do the same thing.

We made a list of questions about aging and housing for people with disabilities. We called this list the FINDS survey. We asked many people to take the survey using a computer. About 5,000 people completed the survey. People from all 50 states completed the survey. Most of the people were family caregivers.

This is what caregivers said about supports. 7 out of 10 families can't find the help they need. 4 out of 10 people with disabilities do not get all the help they need. 3 out of 10 people with disabilities are waiting to get help from the state or county. Some people can wait for over 5 years. 8 out of 10 families can't afford to pay for the help they need. 6 out of 10 caregivers spend at least 40 hours a week helping a family member with a disability. This is like having a second job! 1 out of 5 caregivers had to quit their job to help a family member with a disability.

The good news is people with disabilities and their families can get the support they need. The bad news is that services can be hard to find. Many people with disabilities could not get all the help they needed. Many families are tired or upset because they do not have enough help. We know that all people need their right support to live, work, and play in the community. Scroll down to find out what you can do. Share this information with the people in your life. Show your family members and DSPs and ask them to make sure you are getting the services and support you need to succeed. Show this information to people who make tools for everybody; Policymakers, Self-advocacy groups and providers. Ask them to work together to get the needed support, to live, work and play in the community. In short, to pursue happiness, this is their constitutional right, after all. Scroll down to see who we are. As you can see at the end of each translation that we have done, we do offer people the opportunity to go to the link for the actual study so that both can get more in-depth information if they want. I will turn it over to John and he will tell you a little bit about the process we use for doing our translation and making it accessible.

This section gives you information on the people who did the study. You can find out more information by going to the Internet links.

<http://www.selfadvocacyonline.org/research/>

(John Smith) Our research is vigorous. We begin by doing preliminary research. Where we translate reviews for journal articles. Our next step is to select one or more key topics to these issues. We capture all of the important information then our next step is we take it back to the researchers and begin to do a dialogue with them to make sure we get it right before publish the translation to the site. We involve self-advocates. And we communicate with the researchers throughout the process. Once we have a draft, we take it to our review board. They help us and begin to select media.

(Mark Olson) This project has been exciting for us at the Research and Training Center on Community Living because it's a perfect complement to our core competencies. Through stories, interactive learning, and research translation, we want SAO to become the go-to place for knowledge translation and dissemination. This site offers a great opportunity for all of us to reach self-advocates with good information and for self-advocates using this information. Thank you for attending this webinar on Self-Advocacy Online. We're now ready to take questions.

(Anna Costalas) I'm going to open up the floor for questions. If you would like to ask this question, you can press star and a pound key or you can enter a question in the chat box.

We have one question. With a PowerPoint of this be available on the website?

Yes, we are it is being recorded and will be available on the event page at the end of next week.

We have another question, what will you do to evaluate the effectiveness of the site?

We are doing individual interviews and some focus groups with self-advocates to ensure that we are meeting the needs that they have and making sure we are getting in -- the information in a manner that works for them.

Do you have a sense of how many self-advocates are using the site and how did they find it?

That's a good thing. We have a couple of different ways that people are connecting with us. As you saw on the site probably at the beginning, we have -- we are using our reach where we can. The art is helping us, hopefully you guys are helping us now that you know about it, but we have a self-advocacy online page on both Facebook and twitter and we are constantly posting and sharing information on those sites. Sometimes you will have something where we are taking something that we are seeing on one of your sites and reposting it or we are finding something that we feel need -- meets the need or something we actually have. Of course, the arts information gets out there through this. One of the pieces that I posted on the Facebook page, it has been exciting to see how many hits in shares we are getting. As with social media, we are getting different support and people like to propose and is helping us to refine what kinds of things we looked at.

We have another question, is the website intended to inform people of the services of the agency or one Self-Advocacy activity.

Primarily, what we have developed this site for self-advocates to get information that will be beneficial to them and to have a place where -- a repository for finding each other. As far as agencies specific pieces, it depends on what you are talking about by agency.

Have you connected with the PIL, centers for independent living?

We have connected with them through some of our social media pieces. I am not sure myself if we have had any direct content -- contact with them. It's a good idea if we have not to make sure that happens.

How large is the font size of the website?

Looking on the screen, many of us could not read it even with our glasses. I'm assuming it is because it was in the Adobe Connect.

That is very possible. It is probably because it was there. I'm looking at font sizes and I'm just guessing because I am not the one who sets up the font size. I am getting those guessing they are from 14 or 16 point and some of the larger ones are probably up in that as well -- I will go back to the site real quick and pick up the. I'm saying that is probably 30 to point -- 32 point.

I find your videos of self-advocates and research interesting. Would it be ok if we used some of your research and videos in our trainings?

We would love that. I don't think John had a chance to mention in one of the videos we are looking to actually be a place where you can actually add your videos as well, so if somebody has a topic if they want a video on, we are working on a process for that. Until then, what people can actually do is if you have a YouTube link, of a video that you have done or something that speaks to one of these self-advocate topics, a self-advocate giving information, that type of thing, send us the link using the contact feature on the page and we will say -- see that he gets connected with the video and gets posted somewhere.

We have another question, have you contacted with SABE.

Yes, we actually presented this at the SABE national conference when they were here in the Twin Cities last year about this time. We actually rolled it out in front of them. It was the first time we put it out there to a group. Another question

How do you know your information is reliable?

I'm sure our researchers, whatever we put out, research translations outline in cooperation with the author of the research.

We actually because we collaborate with authors of the research that we are translating, we are making sure that we are working -- staying true to what they are research -- staying true to what their research was.

Is there a way that Self-Advocacy groups and facilitators can get CDs of the videos because they do not always have access, quick Internet access?

Currently, this is a good question, we anticipated this coming, people wanting a DVD or something like that, and we don't have those at this time. The hands are full editing a number of postings and interviews that have already come in and demand is strong enough that in the future, we may have some stories on a DVD, but for now, unfortunately, the linking is the only way we can do it. One

thing that you can do though is if you have access to things -- other platforms, mobile platforms, the site is designed to work with mobile platform so if you have access to an iPad or an iPhone or something like that, those pieces are also going to allow you to do that. For right now, we don't have them in another format, but we have tried to make the site workable with mobile setting so people can access them.

This is Hunter...Another way that they could have access to this for now until we come up with the DVD or whatever they need to have access the research that we are doing together, is through going to the library. For me, I started learning how to do stuff like that because I used to go to the art office and they would have their computers there where I could access information like this. That is another thing because not everybody has the technology.

We do have another question; does your website translate into Spanish?

I would have to get back to you on that one. I don't know that we have a Spanish translation that we have developed, but there may be a process that that can be done. I would have to ask our web folks about that.

John says we have not done that yet.

We have another question, they were reading research on how is education going. Did you have any findings on students being included in their IDP and transition planning meetings?

I believe that was in the report. We did not include that.

That was not specifically included in this translation; however it was in the report. One of the things that happen with the way we do this trip research translation is there is always a lot of information in a research paper that we are working on. And so we try and hit some key points. That is why we leave the link to the full research so if there is a specific piece that you are looking for that may have been there; you can go right to the actual source.

It's a difficult, difficult balance between getting all the information without overwhelming people.

Right, we don't want to overwhelm. -- Good question.

Someone said it looks great to her.

Great to hear that!

We are always open to feedback. Use the content piece that is on the page and let us know. Contact any of us at the RTC and we will get it to Jerry or John or Hunter or anyone who was working on it.

This webinar is being recorded and live captioned. We will have this transcript and recording available on the event page after the webinar.

Also, at the end of this I will send you a copy of our script slides so that they will help you making sure the translation goes through.

Perfect.

We have another question. How can organizations work with SAO to have lessons created, research translated?

We are hoping to have that happen. We want to be a go to for that to occur. Currently, we are working on an old grant that is no longer in place, so it's a matter of us doing this as not only part of our RTC, we are hoping to do translations with other organizations. We have taken a test run on the time it's taking for our team to do things, I will give you a couple of numbers here. It costs approximately \$2000 to translate research so that is the research to write a lesson it is probably about \$7500 to programs. We are looking at some sort of partnership where we can do some cost sharing or whatnot to make these things happen. But there can be some scale savings I would expect if we have a number to do with somebody, we can probably work some more things out. The process it takes to do this is about two or three months. We try to be more rigorous. From research translation, like John said, we do rigorous read-through to begin with and then it starts going through the translation process where we use our editorial team, self-advocacy editorial team, and our in constant contact with the author to make sure that we are meeting the requirements of the research. It takes a little bit of time to make sure we are getting a quality product posted.

How are self-advocates involved in editing the content?

The process that we are using now, we are hoping to expand this, as we get more equated -- acquainted with the technology, that we need to use to get into a meeting virtually, we are hoping to add more self-advocates to our group. What we do is have a once a month meeting where we go through the different pieces that are being translated and we go through and review what is going on at the site to see if there's something that needs to be between and then we are in constant -- suite and then we are in constant contact with the team that is part of the editing to see if they are seeing anything and are sharing with us what might need to be changed to make it work better.

How can self-advocates' get involved?

You can actually e-mail me or contact us with a Compaq piece on the page. I would love it if you contacted us to the page because I think people getting people to the page are important for us. Use the contact feature on the page that you would like to get involved and let us know where you are from and what you're self-advocate affiliation is, if you are with a group or just yourself or whatever and we would love to see if you can start working with us on some capacity.

Do you take suggestions from others about the research you translate?

We are always looking for input as far as what we should be translating. Our initial choices were based on Surrey results to some self-advocates, -- survey results with self-advocates. We seek the best information possible. And partners help us choose the topics but we are always looking for, if you have input, give it to us and we will throw in the hopper and see what kind of buzz there is around that specific topic and who knows, something you suggest may come around. And something we -- at something we translate.

Can we connect with SAO through social media?

Absolutely, we do have a Facebook page and we do have a twitter account. If you go to the website itself, self-advocacy online at the top you will see the Facebook and twitter logos, if you click on that, it will take you there and you will be able to connect to our ace book or twitter sites. -- Facebook or twitter sites.

How did you get the research info to you? What is your contact information?

I will give you my contact information for right now. And we will get it going through the process. My e-mail address is olso4541@umn.edu. You can e-mail me and I will make sure that whatever you have to share we will give to the research translation team.

There is a question, if you worked with CQL

We are not at this point working with CQL.

Someone suggested that the sibling leadership network would be interested in connecting.

If they have contact information for someone from that network, share it with us and that would be great. Otherwise I will do my best to look them up through.

Someone else asked if you are including info on autism?

We do not have a specific piece on here right now on autism but if you go to the actual Facebook page, we are constantly putting things out there that we find. Yesterday I posted an individual self-advocate in the autism spectrum story on that. It's a video story that he is telling, five-part series that is really interesting. We will include those pieces, I do not know yet what will happen what we translate for research are what we do for the learner about pieces because those are types of things that are being -- we are figuring out from self-advocates what need to be the topics.

(Anna Costalas) Those are great questions. Thank you for presenting. I would like to thank everyone for attending the webinar. This webinar has been recorded. And it will be archived after -- from 7 to 10 days, at the webinar library AUCD.ORG if you have -- if you want any information about NCEDC please contact us. Please take a minute to take the survey once the event has ended a survey will pop up on your browser. Thank you very much everyone. Have a great weekend. Thank you everyone.