>> Shelly Christensen: Hello and welcome to the fourth and final webinar in the AAIDD Religion and Spirituality Interest Network 2023 series, called "Pathways to Belonging: Supporting the Spiritual and Faith Community Interests of People with Intellectual and Developmental Disabilities." And I'm Shelly Christensen. I'm the Senior Director of Faith Inclusion and Belonging at RespectAbility, and I also have the privilege of being a member of the Religion and Spirituality Interest Network planning team. My pronouns are she and her. I'm a white female, and I have dark, curly, shoulder length brown hair, and I'm wearing purple frame glasses. I'm wearing a black, white, and pink polka dot sweater. And behind me is a gray wall, a Tiffany style lamp, and a purple, red, green, and gold abstract painting. RespectAbility's Faith Inclusion and Belonging department and the AAIDD Religion and Spirituality Interest Network have collaborated on this important series. RespectAbility is a diverse, disability-led nonprofit that works to create systemic change in how society views and values people with disabilities. We are the only national disability organization with a department centered on multi-faith inclusion and belonging. The AAIDD Religion and Spirituality Interest Network works for recognition of the importance of religion and spirituality in the lives of people with intellectual and developmental disabilities across faith traditions. The webinar is being recorded and you will receive the link via email afterwards, and along with a survey. And we hope you'll take a few minutes to respond to the survey. And that will help us -- that will help us plan our 2024 series. So just to go over our accessibility notes, you can turn on the captions with the CC button in Zoom. And the CC button will be on the bottom of your screen where it says show captions. You can pin the interpreter to ensure they are visible throughout the presentation. And to view live transcript in a separate window, there is carolina captioning -- there's a link -- there will be a link in the chat box. Ben, if you could get that please. And then I ask that you put your questions in the Q&A box so that we can get to them at the end of this webinar. And so the open captions will be added to the recording, and you'll find that at RespectAbility.org AAIDD 2023 series -- link in the chat box. Just to give you the focus here on this webinar, it introduces direct support professionals and service providers to use the facilitation skills they already use in job and vocational searches as well as social and recreational participation to address faith, religious, and spiritual needs and interests. This supports individual and meaningful participation by people with disabilities in their spiritual communities, opening doors to many opportunities to be included and to belong. Religious and spiritual -- and spiritual organizations and faith communities provide networking opportunities for jobs, housing, and transportation, in addition to the social, emotional, and connectedness that all of us seek. By the way, the National Alliance for Direct Support Professionals and the Religion and Spirituality Interest Network offer an e-badge that addresses the journey that DSPs take with the people they support to discover their religious and/or faith communities. And it is our hope that DSPs who participate in this webinar series will begin to facilitate this important work with the people they support, as well as take time to address their own spiritual needs and well-being. Please join me today in welcoming our esteemed presenters: Anne Masters, Shea Tanis, and Rabbi Alan Cook. Anne, take it away!

>> Anne Masters: Well, hat was fun. My name -- hello, my name is Anne Masters, and I'm -- I use the series -- the she series of pronouns. I'm a middle-aged white woman with dark brown hair that has some narrow streaks of blonde and gray. I'm wearing clear framed glasses, a black sweater, multi-colored scarf, and a necklace with a black and white cross on it. Behind me are bookcases with books on it, and also a picture of me greeting Pope Francis and giving him a book. I live with ADHD -- explains some of my distractedness right now. Anyway, I'm the Director of the Office for Pastoral Ministry with Persons with Disabilities for the Catholic Archdiocese of Newark. I've been a member of AAIDD and its Religion and Spirituality Interest Network for 17 years, and a past president. My PhD work has a focus on the intersection of theology and disability, particularly in the areas of the influence of narratives that continue to marginalize persons with disabilities in faith communities, and then how to counter this within a constructive framework that supports participation in valued roles that will promote appreciation and meaningful participation as integral members of their faith community. Faith communities are essentially frontier spaces for using technology to promote participation and nurturing personal and communal aspects of spirituality for persons with disabilities. So my role today is to provide some context for our conversation. Then Dr. Tanis will speak about creative ways that technology is being used to increase participation in community settings. And then Rabbi Alan will share ways that he and his congregation at Sinai Temple have supported this. The picture on this slide is a -- it's an unpopulated circuit board -- that hasn't been populated yet with computer chips. And it's laid out to support the interactions and communications between the different electronics, once it were to be assembled. And I thought it kind of served as a useful image of the potential for us based on the interaction of people and technology. So spiritual assessment domains, meaning, and core questions. There's lots of information on this slide, and I'm going to just -- I'm going to focus on highlights for you to refer to later. But as professionals, you depend on good assessments to develop a useful plan of services that are going to enhance capacity and participation in life for the people that you serve. So the importance of spirituality within a holistic framework of human beings is now well documented in much research. However, it's still absent from many of the standard assessments for persons with intellectual and developmental disabilities. Bill Gaventa gives a brilliant discussion of this subject with many useful points and references in "Disability and Spirituality: Recovering for Wholeness," where -- actually which I was drawing from here. And Bill synthesizes questions of -- of spirituality within the three questions in the right hand column. Who am I? Why am I? And whose am I? But for meaningful assessment, you're going to have to require -- break it down a little bit more. So the one that I like the most is displayed here in the left two columns, and it's the seven by seven model by George Fitchett, whose work focuses on promoting evidence-based practices in spiritual care. So he defines spirituality as the dimension of life that reflects the need to find meaning in existence, and in which we respond to the sacred. It provides the seven dimensions of holistic assessment that would look at biological, psychological, family systems, psychosocial, ethnic, racial, cultural, social issues, spiritual -- and spiritual aspects of a person. But then to break down what the actual elements of spirituality, he says it's belief and meaning, their core values, vocation and -- obligation, sense of calling, experience and emotions, how one experiences the divine, courage and growth was the sense of hope and source for changing beliefs, also ritual and practice is both personal and communal. Community -- where and what our information -- the networks that are formed. And then also authority and guidance -- what's the source of beliefs. So -- now these correlate well to personal outcome domains such as self-determination, full citizenship, education, lifelong learning, productivity, well-being, inclusion in society, and community living and human relations. Often attending worship is the only one that's considered under community living. And I'm not going to go into all the possibilities, but I just want to suggest if you were to consider full citizenship -- the right to choose in this area. Separation of church and state means the state doesn't determine someone's religion. However, if we're not including spirituality and faith within someone's life, it's actually a way of denying their perspective of -- and spirituality of the human person. So I'd like you to think about this as Dr. Shea and Rabbi Alan are sharing their possibilities, and then you can use this slide to refer to later. Human beings are -- we are innately social and interdependent. And belonging is a human -- is a basic human need. So these are -- these 10 dimensions of belonging that Eric Carter and colleagues have identified are organized in -- four clusters. You know, being present. The second cluster is really -- refers to hospitality to be accepted, and then to be supported, and really appreciated. All of these contribute to a sense of belonging. But to be understood -- and being understood is a part of all this, right? But -- and communication is critical to this process. Spirituality is an extension of this, and -- and also that -- the holistic plan for holistic planning. But there is a perspective that some people -- that individuals with disabilities are innately spiritual, and so sometimes it's not -- which I think is why maybe times it's not given attention for investigation. But I think it's helpful to know that in 1974, Wolf Wolfensberger was surprised to learn about -- to see the benefits of actually nurturing spirituality with persons with intellectual and developmental disabilities, how -- the importance of it in their lives and the effect on their -- the effect on them that it had. And so from then on, he actually recommended it be a part of residential living. He had observed this at Larsh Daybreak. So, how can we communicate without a voice? Dr. Shea is going to be talking about this more. I just want to reinforce how critical communication is as part of supporting someone's exploration of their spirituality. And I want you to be thinking kind of throughout our conversation today, can someone belong without a voice? And know that your work is critical. Your role is important. In general, faith communities are not comfortable with using different kinds of technology, or with interacting with people with disabilities if they haven't had previous relationships. So -- it's -- while they not all do a great job of living the faith they proclaim, but it's often because of a lack of knowledge, not desire. And also for a a fear of not doing things correctly. So your work is going to be important in demonstrating the capacity of persons with disabilities, and helping them to know about the importance of supports and reasonably high expectations, also helping to diminish the charity model of disability which is pervasive in faith communities, and nurture connections and natural supports so that your presence can fade over time. And if a person is preferred -- an in-person is preferred over virtual when at all possible. So recall that within faith communities, there are many possibilities for participation. Across traditions -- there's the recognition that human people are created in the image of God, and that this is the source of respect and communal responsibility. So you -- don't have to worry so much about is it acceptable or not. But then person-centered planning and identifying natural supports is consistent with this. And think of roles for participation, rather than tasks. And then looking at the opportunity -- the different opportunities for participation: there's worship, choir, social justice, Fellowship, service, education/formation, the list could be endless. But then if you have not -- if you're helping someone to find a faith community, it's good to get a sense of it ahead of time by checking out their website, their bulletin newsletter, and also contacting leadership, the Rabbi, Imam, or the pastor. And now I am going to turn it over to Dr. Shea. And am I stopping sharing at this point?

>> Dr. Shea Tanis: No, we're moving straight on, and thank you for the transition and introductions. And it is a pleasure to be with all of you today. I want to thank our hosts -- our gracious hosts in doing this, as well as an incredible partnership that is occurring between two different AAIDD interest networks to make this possible. My name is Shea Tanis, as introduced. And I will be sharing some interactions around technology in the space of spirituality, religion, and faith. Next slide please.

>> [voiceover] Sure thing!

>> Dr. Shea Tanis: So the -- my technology is telling me, sure thing! [laughs] So technology certainly is ubiquitous throughout our communities now. We're using it as we speak, to engage with one another, to feel connected. It is truly changing the world around us -- how we interact, how we survive and thrive within the world. But some of this changing means -- some of the perspective is that it may even be shifting the way we interact and what it means to be human. In this conversation, I want to be clear that there has been both conflict and harmony between technology and religion and spirituality that has spanned centuries. The new applications of technology solutions are making it difficult to ignore what are the scientific advancements that could benefit faith communities in being able to expand and empower individuals with intellectual and developmental disabilities. So we will engage in some of that conversation today. Next slide please. So we're thrilled to be able to present this information to you. This is a partnership between the Religion and Spirituality AAIDD American Association on Intellectual and Developmental Disabilities Interest Network, as well as the Technology Interest Network. And we're thrilled to be able to demonstrate where we can have cross-pollination of ideas and innovation in this space. Next slide please. On the 25th anniversary of the Americans with Disabilities Act, the American Association for Intellectual and Developmental Disabilities and the America -- or the Association of University Centers on Developmental Disabilities came together to examine what do we know about community living after 25 years of investments in research and practice. And it came out that there are several domains of high quality community living for people with intellectual and developmental disabilities. And in those -- you will see on your slide a diverse grouping, a infographic that shows decision making, where to live, relationships, personal interests, health and wellness, daily activities, employment, education, decision making, but also worship. And that's very broad right, so that means more than just worship. That means faith, spirituality holistically. But the point being that it is a major component that needs to be considered when we are thinking about the individual's access to real community living. Next slide please. So we begin to think of how do we experience the world around us, how do we practice faith and spirituality? How do we engage? And so as I said we're not going to get into any of the discussions around the conflicts between religion and science, but yet how they can blend together to empower individuals. So we will be talking about the -- I'll be talking very much around the functional applications of how can we use technology to the greatest benefit. And we've already seen over the span of the last two years some real expansions, and really, the catapult of what is the utilization of technology solutions to gain access and empower individuals. And this also applies to faith communities in their utilization. We had seen through the pandemic many new types of virtual services, meaning virtual religious services and practices engaging with one another. Meditation technologies used for well-being and wellness, many e-verse or electronic books that allow for folks to look at scripture and engage in that, as well as looking at the ethics of technology solutions, and how do we look at the conflicts but also the discussions of using technology ethically to allow for freedom of expression, allow for knowledge-based acquisition in this domain. And I think that's an important thing to understand, because as we see some of these advancements in technology, as we see some of the advancements in machine learning and artificial intelligence, we see that you -- they do have some bias and that does not not go -- that's not -- that's still experienced in faith communities as well. When we look at information and sharing of information, technology is biased when it is programmed by an individual, and that's what AI algorithms are. And so taking into consideration what could also be religious bias or the connections of, say, terminology and how it reflects in someone's search engines to explore faith. This is an area that still can impact the community. And it's one that should be considered as we use technologies to expand people's access to different forums. So this is some of the experience we've had. Next slide please. And so when we're going to talk about the real applications of technology, and we're going to talk about what are the inputs, how people receive information and the many different technologies that can be leveraged by faith communities to reach out to individuals with intellectual and developmental disabilities. Oh, I'm sorry. There I am. As well as the outputs of how individuals with intellectual and developmental disabilities can use their own technologies to be able to engage with their Community. Next slide please. So how have individuals received information, what are the different sensory inputs that have been utilized to be more inclusive, using more universal design for individuals to access technology in the faith religious spirituality space? So we've seen a lot of delivery -- digital delivery of information. The value of this is many of these platforms already have baked in or accessibility features, so things like speech to text, text to speech, and large font sizes, that have already allowed individuals with disabilities to access information that they may not have been able to in the past. We've also seen access through connected communities. The pandemic taught us that we can be more connected in virtual realms with giving adequate space for individual transmission of the pandemic or COVID-19, but allowed people to stay connected in different ways. Social media -- we talk about networked communities or connected communities engaging with one another to support. And much of that, we learned through the pandemic, also allowed support of religious and spiritual and faith information, as well as getting people to different types of communities to be able. It was a sense of togetherness that we may not have had if we did not have the digital forums to be able to engage. And that's really important, because so much of spirituality, religion, and faith is about being connected, and looking to the technologies as a conduit of keeping people connected. We've also seen -- in the image on this slide is a pastor with a virtual headset on, a VR virtual reality headset on. We've seen many uses of mixed realities. Mixed realities includes virtual reality, augmented reality, as well as a blend of those different types of virtual platforms. But this is being engaged with in another sensory modality, to be able to engage individuals who may not be able to have access on the ground in person, and the pandemic prevented that for many. We certainly want to make sure that there is a note here -- and I -- Dr. Masters also talked about it -- that we don't want technology to replace connectedness, but we want to use it to enhance connectedness and together -- togetherness. So these mixed realities are used as an addition to, enhancement of, what are getting people connected. Haptic touch is the next sensory modality. Haptic being the sense of touch that can be used. You think about how much of religious services engage the sensories, engage the sense of touch. And haptics can be used when one cannot be physically present. And so this is another modality, another sensory modality that can be leveraged by communities to be able to access or provide access to those who didn't have access to their knowledge base, their teachings before. We've also seen for many who cannot interact with traditional instrumentation, or instruments, musical instruments, being able to use digital instruments to be able to contribute or be able to share that experience. Because that again is another form or another strategy and technique used by faith communities and are very integral to those services and communities. And using different ways to share expression in digital music. And then finally, we're seeing more and more of the advancements of artificial intelligence, doing sermon builders and religious searches. This is something I mentioned earlier. You know, the chat-GPT that we are seeing blowing out of control in terms of interest, you know, gives us some exploration around religious texts and faith communities. But it also can be enhanced. And I would say that as we move into thinking about technologies not replacing humans, but that humans can use it as a tool. And you'll hear some conflicts as we look to the sharing. There are also, I will tell you, a number of new robots that have been created, certainly accelerated by the pandemic. Robo Rabbi, Santu, and the Buddhist Canon. Those are robots that have been introduced to be able to share faith in different forums. Next slide please. But most importantly too is people's individual empowerment and engagement. How can technologies allow for individuals who may not use traditional techniques for engagement leverage that so that they do have a role, they do have a means for engagement. Communication technologies have provided an incredible platform for individuals who do not use traditional speech to be able to share their mind, share their faith. These are in various forms of expression. It also -- we've also looked at technologies to enhance that connectedness. Looking at individuals, sharing connection through their accessible formats, and through their technologies. Certainly new technologies that are used for digital art, digital music, and haptic touch can also be used for expression. So those who did not have a forum of expression in traditional means may use these alternatives to showcase their faith, to showcase their spirituality. And finally, I do bring up transportation and navigation, because for so many, transportation can be a challenge of staying connected with spiritual and religious services and faith communities. We now have technologies that can help provide the support to get them to those forums. So we just talked about, very briefly, what are some ideas or some solutions, not only for religious practitioners to use or faith practitioners and faith communities to use to access and share information to the intellectual and developmental disability community, but also ways that others can share their own love and faith through technology expression to their communities. Next slide please. And if you're a practitioner, there are ways to begin to identify technologies. As Dr. Masters talked about, you know, we always take this person directed approach for identifying -- not only access to faith but also access to technology solutions. And the easiest way to begin that is look at where is the first goal, what is it that the individual wants to enhance in their life? And if spirituality is something -- you start there and identify the solutions that help them to get there. That is some of the process. It's a person directed process that empowers the individual to use their own solutions to achieve the goal of spirituality and faith. Next slide please. And so some of the things for practitioners to begin to think about for the future: the emerging disruptive technologies and how they apply to this community. There's certainly new spirituality technologies coming out every day. As ubiquitous as technology is, the faith communities have also begun to embrace and allow those technologies to be used. And you're going to hear some wonderful stories from Rabbi Alan Cook around the practical applications of the spiritual technologies and how to use communication technologies in new ways to provide harmony and access. Certainly using data -- we see even faith communities using information on how to access a broader community. What are the solutions that are supporting more connected environments, more connected communities? And that's something we're seeing utilized at a greater levels, still through spiritual and religious services. And then also this virtualization -- converting everything into what could be digitized or computer programs. But I don't think that we can forget what is, kind of, the conclusion here. Next slide please. Which is that -- and this comes from Rabbi Joseph -- Joshua Franklin, who says, you know, people are going to realize that human beings are no longer the best purveyors of information, but what they can do makes them distinctly human are those things that are precisely in the realm of religion and spirituality. And I want to transition to that, because I think Rabbi Alan Cook is going to speak very eloquently to how to entwine spirituality and technology in some of his practices. So thank you for your time, and I'm going to hand it off to Rabbi Alan Cook. Next slide?

>> Rabbi Alan Cook: Thank you, I am honored to have been invited to this presentation today. My name is Rabbi Alan Cook. I am Rabbi at Sinai Temple in Champaign, Illinois. I am part of the reform Jewish tradition of Judaism, which tends to be a little bit more on the liberal perspective -- that has nothing to do with politics but in terms of how we apply our faith to modern life. I use the he/him series of pronouns. I am a white male with black rim glasses and short black hair. I'm wearing a gray suit with a blue shirt, pattern necktie in shades of purple. I'm in my office at the temple right now which has bookshelves behind me and quite a bit of office clutter. But again, I'm delighted to be here. One of the things that Dr. Shea lifted up in the last few moments was that there can be both conflict and harmony with the use of technology, particularly in religious spaces. And it can unfortunately happen that people abuse scripture in terms of dealing with groups that they wish to find in the minority. And -- if I can have my first slide, the next slide please. So this is the first biblical passage that I'll lift up. This is from chapter 21 of Leviticus versus 17 through 23. And this is when Aaron is getting instructions for him and his broader family that are going to be in the priesthood of Israel. And basically says that anyone who has a disability is disqualified from service to the priesthood. And some have lifted that up to say that this is a disqualification altogether from participation in a religious community. There are many different ways that we can apply modernity to it and modern understandings in order to -- to reconcile this. But I think that it is important to say that even though there have been unfortunately those abuses of the community of disability, that we need to find ways to embrace. My Jewish community -- my local Jewish community, and for better or for worse, a significant portion of the North American Jewish community is middle class to upper middle class, largely white presenting. And there can be a tendency to sort of imagine -- when you get in the larger levels of the congregations and congregational politics, that everybody is on a normative scale and that we don't need to pay attention to disability awareness and therefore the innovations that need to go with them. And that is actually not at all true. It's probably not easy to see in my little image on Zoom, but I wear bilateral hearing aids, I have a moderate to profound hearing loss. Two out of my three children also wear bilateral hearing aids. And so, in my own family, in my own personal experience, we are dealing with different ways of experiencing our spirituality, and therefore different thoughts about accessibility. So if I can have the next slide please. Now in traditional Judaism, and as I said, I tend to be on the more liberal end of the spectrum in terms of how I approach my Judaism through a lens of modernity. But in traditional Judaism, another complicating factor in inclusion is that we have this passage from Chapter 35 of Exodus. We have it here both in the Hebrew and in the English. I'm going to spare our interpreter Bill from having to interpret this in the Hebrew, and just read it in the English. "You shall kindle no fire throughout your settlements on the Sabbath day." So the Jewish Sabbath runs from Friday evening to Saturday morning that's how we -- to Saturday throughout the day I should say. And that's how we understand the Sabbath day. And this prohibition against kindling fire on the Sabbath has traditionally been applied to not making a spark of any kind, and therefore not using electricity -- now at the very least, not using electricity in such a way that one during the Sabbath hours takes an active role in making electrical current flow, in making electrical appliances operate. And so that became a complicating factor as technology became more and more -- not just a luxury, but became an actual necessity in producing worship services. What do you do about a microphone? What do you do about writing in a sacred space? What do you do once COVID hits and the only way to continue to network in a safe way is perhaps to approach technology and to do things like live streaming or Zoom or YouTube or so forth? And so we did have to encounter that. If I can have the next slide please. So beginning in March of 2020, you know, there was that first week when we didn't really know, you know, how long the pandemic would impact us, at least here in the United States, in which I gathered with my musicians and we huddled around my laptop and we -- sorry, I'm getting a time warning, so I'm going to try and go quickly. But we began to -- we did our live stream that way. But by the following week, it became clear that we would need to adapt. And so we began to build these PowerPoint slide shows with our liturgy. What you're seeing here on the screen is one of the slides that I prepared for sharing our liturgy on a weekly basis. And this mirrors the way that it is in our prayer book. So already, even before screens we were thinking about accessibility in our prayer books, because not every North American Jew is fluent in Hebrew. So we have the traditional Hebrew on the right side of the page, we have a transliteration -- the Hebrew rendered in English characters -- on the left side of the page. And then we also have a translation in case you want to know what it is you're actually saying. We have that at the bottom of the page. So we have instilled screens, and that is one way that we have been able able to increase accessibility. If I can have the next slide please. So this -- I want to offer three sort of personal examples. This is my friend and congregant Ray Spooner --Raymond Spooner, in one of his healthier moments. He is wearing a traditional prayer shawl, traditional Jewish prayer shawl, and he's also wearing a bike helmet, and this very much represents his personality and his intersectionality between his Jewish identity and his identity as an athlete. And he also happens to be holding a cup of tea, because he was British by upbringing, and always told me that he needed to know how to make a proper cup of tea to interact with. In December of 2014, Ray was diagnosed with ALS. And so as ALS began to take its toll on his body, he had to think about ways to continue to have access to our religious community. So if I can have the next slide please? So this is Ray on one of the last days of his life. It's a beautiful black and white picture that I have in my office. It may be difficult to fully see what's going on here, but because he had no muscle tone, particularly in his neck, he could not hold his body up at that point. And so he is leaning his head on my sternum for support. And I was able to offer him a blessing in that context. But I want to lift up this quote that I also have on the slide here. "I am Ray Spooner, and this is my voice." Because Ray chose Judaism in his adult life, and therefore never celebrated the -- as a teenager, the coming of age ceremony known as a Bar Mitzvah. And so when he created his bucket list, which he referred to by a more profane name that I won't share here -- when he knew that ALS was going to rob himself -- rob him of his faculties, and that this was something that he really wanted to do, he scheduled to have an adult Bar Mitzvah. And on the next slide, I want to share share with you one of the things that he said during his Bar Mitzvah.

>> Raymond Spooner: Hey.

>> Congregation: Hey.

>> Raymond Spooner: This week’s Torah reading is Devarim. It was the Parasha that was read the week I was born in 1959. Devarim means words. This is the beginning of Moses's final address to the people of Israel. He's sharing his knowledge of the last 40 years with a new generation. In a way Moses is imparting his legacy around his words; his devarim. [Speaking in Hebrew] “These are the words which Moses spoke unto all Israel beyond the Jordan; in the wilderness, in the Arabah, opposite Suph, between Paran and Tophel, to Laban, and Hatzeroot, and Di-zahab.” Moses did not consider himself a great orator. In fact, he described himself as "slow of speech and slow of tongue" and having "never been a man of words" (Devarim) But the book of Devarim constitutes one powerful and sustained verbal presentation. This is the information he wanted to impart to a new generation before they crossed over into the promised land because Moses knew he wasn't going with them. My name is Ray Spooner, and this is my voice. Like Moses, I've never been a man of words. And some would also say I'm also “slow of speech and tongue.” At least they would if they could actually hear anything I said. But for better or worse, this is my voice. It probably defines me more than any other personality trait or characteristic. Ever since I remember people have seemed to have an opinion about it. [congregation laughs] Even back in school, classmates and teachers alike would refer to me as “Mr. Mumble.” [congregation laughs] As an adult, people seem to be divided into two camps. There are those who find my voice calming and reassuring, and there are those who genuinely believe that I speak this way for the sole purpose of pissing them off. [congregation laughing] But, regardless of where you fall, it’s just my voice. It’s part of who I am. The reason that Rae and I chose to have this event this year — sorry — is because I have a disease that is, amongst other things, taking away my ability to speak. Eventually, my voice will be taken from me altogether. But before that happens [congregation laughing] like Moses, I have a word or two that I would like to share. My name is Ray Spooner, and this is my voice.

>> Rabbi Alan Cook: So my apologies that this was difficult to understand Ray, both because of the quality of the recording, and because at this point he had been impacted by ALS. We do have a transcript of this and we will make sure to to share it with the future recording of this session. The main point that Ray was making in this presentation was that it was particularly poignant for him to be reading from the portion of Deuteronomy -- from the beginning portion of Deuteronomy, where Moses, a person who is slow of speech historically, was sharing some of his final words and thoughts knowing that he would not go into the promised land. And similarly Ray was feeling that he wanted to share some things while he still had the opportunity. You will see that Ray's left hand is resting on the lectern, he didn't have a lot of muscle tone at that point, so he had to sort of plop it up there. You heard his difficulty with voice. But we still wanted to make sure that we gave him the tremendous honor of being able to have this Bar Mitzvah. I should say that one of Ray's roles at the synagogue was tutoring other young people, other 12 and 13 year olds, to prepare for their Bar Mitzvah or Bat Mitzvah. And so this was a way of sort of, you know, coming full circle and participating in that manner. So Ray unfortunately passed away in August of -- I think it was 2015. He has a wonderful blog, sort of chronicling his battle with ALS and his philosophy on on life. It's called rayslittelride.com, and I'll make sure to get that URL to the organizers of this presentation in case you want to check that out. The next story I want to share real quickly, if I can get the slide to advance. So this is a speech and illustration from a young man named Moses Fisher. Moses' mother Kim, I understand, is very involved in AAIDD. She was the connection that helped me get to this presentation today. And Moses celebrated his Bar Mitzvah also during COVID. Moses is one of four siblings, and three of them so far have celebrated a Bar or Bat Mitzvah with us. And each of them has been different. And I emphasize that with every parent and every student, regardless of what their abilities and disabilities may be, that I want to make everything unique. So it's, you know, it'd be slightly untraditional in a more traditional synagogue to see a picture of Anakin Skywalker while you are celebrating this coming-of-age ceremony. But Moses' most comfortable form of expression was through his artwork. And so he wanted to have a way to lift that up. And he was able to connect -- and I'm not going to read the entire transcript that's on the right side of the screen, but one of the things that he pulled out of his Torah portion, his scriptural portion was about respect, and eliminating suspicion. And so for him, that reminded him of Anakin, and Anakin's turn to the dark side. And so that is what Moses chose to focus on. And we were able to take what had been a very uncomfortable moment, because traditionally a Bar Mitzvah is focused around public speaking and that's not a comfortable practice for Moses, to allow him to lift up his visual expression and his talents and to be able to show that off, and have a feeling of fear and anxiety perhaps elevate to a feeling of being able to show off one's talents. The last example that I want to share -- so this is a mandala from a person that I just met in my preparations for this seminar. And I only have virtually met her, but this is from Pam Falcon Kennedy. Pam Falcon Kennedy is a disabled Jewish Native American journalist, instructor, advocate, patient researcher, and first responder from Bismarck, North Dakota. And she has a neurodegenerative disorder. She utilizes an iPad, as well as the same voice technology that Dr. Stephen Hawking did. There are not synagogues in Bismarck, North Dakota that are operating, so she participates online in a large synagogue in New York City called Central Synagogue. And they have an online program for worship participation called "The Neighborhood." And so Pam was explaining to me that she, while worship is going on, she listens to the music and she has a sort of sketch pad program where she can select the colors and the brush strokes and brush size and so forth. And she directs it. And the program creates -- through mirror images -- creates these mandalas. And that is her expression of worship. Just to quickly summarize some of her disability -- she has very rare genetic errors in her metabolism, autoimmune disorder, developmental disabilities, enzyme deficiencies, and Mosaic syndrome that cause her to be allergic to everything. So it's often known as boy in a bubble disease, and she is impacted in a number of ways. And so as such -- she is trying to use this adaptive speech device, similar to what Dr. Hawking used. And she, by the way, wants to offer her resources that would be helpful to anyone. She is at pam.kennedy@live.com. But she, through her eye movement, is able to use these devices. The problem is that Jewish worship is typically conducted in Hebrew, which is a non-Roman alphabet language, non-latin alphabet language. And therefore, it is difficult to get these adaptive devices to speak in a way that would work in a Jewish context. So I'm going to share two videos, hopefully the audio is a little bit better. This first shows this is one sort of speech set that is pre-loaded into her device that allows her to wish "Shabbat Shalom," a good Sabbath to the community.

>> Voiceover device: Shabbat Shalom, and thank you Central synagogue.

>> Rabbi Alan Cook: So -- obviously you don't see her on the screen, but by using her visual cues that she is able to still operate, she is able to activate that. Secondarily she has -- as I'll play in a second -- she has programmed her device using transliteration, so setting up the syllables that sort of mimic Hebrew pronunciation, she has been able to program it to say the words of a prayer known as the Shma. Which means, "hear oh Israel, Adonai is our God, Adonai is one." It's sort of a central prayer of Judaism. And she is able to program it. But as you'll hear it moves at a pace that is not fully mimicking of normal human speech, it does not sing, and so having it feel like participatory prayer, this is about as good as she's able to get it right now.

>> Voiceover: "Sh'ma Yisrael, Adonai Elohainu, Adonai Echad."

>> Rabbi Alan Cook: So she tells me that she's been playing around with adjusting the speed of it, adjusting the the pitch to make it sound, you know, more feminine. But you know -- and we have the additional layer of when you are on Zoom or when you are on a streaming service, having multiple voices come through at once creates an electronic cacophony that can't be understood. But this is her means of participating in worship when she is quite literally otherwise in somewhat of a bubble. And so the fact that Central Synagogue has allowed -- has enabled this form for her to be able to participate, we do -- so, you know, similarly on a smaller scale in my own synagogue, by offering a YouTube and Zoom connection for people to be able to participate across the miles. But there are certainly a number of devices that we can utilize that help to allow for this, but there are also still quite a number of limitations. So I'm going to stop there. I don't know if we have any questions in the Q&A section or other things that people want to share as we wrap up.

>> Shelly Christensen: Thank you so much Rabbi. This is Shelly. I'm going to ask our presenters to turn on their cameras please. And because we got a late start, let's look a little bit at some of the questions that came in very briefly. Rebecca asks if there are any suggestions for faith communities which meet virtually. And Shea, can you just share your answer?

>> Shea Tanis: Sure I went ahead and -- absolutely, I went ahead and add some answers in the Q&A. To be brief, one of the key pieces is making sure that any platform you are using for your virtual platform does have baked in accessibility features, so that when you are using it, others outside the community can also engage. Also within those virtual platforms, ensuring that your community members that may have cognitive disabilities understand how to use them. And to do that, understanding that there may be a little bit of technical assistance and training to ensure that we are not creating barriers for them to engage in your virtual platform. And then finally, really looking to allow individuals with different types of disabilities, cognitive being one, to participate when you are in a virtual platform. Sometimes that means simply being able to raise their hand in a different way. That may mean using not only speech but type written, making sure you have captioning involved, but allowing multiple opportunities for engagement. There are strategies to do online and virtual platforms that are not just simply voice output, but ensuring you can do that in your virtual platform so it is inclusive.

>> Shelly Christensen: Thank you Shea. And Dave asked is ALS an example of one of the disabilities we're talking about? And I think AAIDD Religion and Spirituality Interest Network focuses more, is centered more on intellectual and developmental disabilities, but Shea also responded to that question as well.

>> Shea Tanis: Sure, sure. So some features of ALS can be cognitive disability, and we look at -- when we look at the applications of technology, we also look at the function that the technology can support. And that crosses disability categories, and disability diagnoses. So I think what we're trying to introduce here are a variety of different strategies, approaches that may not be specific to a diagnosis, but are specific to empowerment for people with a variety of different technology needs and cognitive disabilities, and disabilities general.

>> Shelly Christensen: Great thank you so much. Anne, you have a comment as well?

>> Anne Masters: Yes, just building on what Dr. Tanis said. You know, one of the -- it was interesting when we were planning this, it was very challenging to find individuals with intellectual and developmental disabilities who are using communication devices in their faith communities, either that were feeling -- because those that we knew that were, the situations were so fraught with tensions, and that this really is the frontier area. And so -- and because of the importance of spirituality in persons' lives, that's why we wanted to bring, you know, what Dr. Tanis could share in terms of the practicalities of it in supporting, and then also Rabbi Alan's, you know, real life examples. And to remember that in your roles as professionals, it's really guiding the community -- the faith community, educate the -- educating them about how, but then also modeling. And allowing, for example, to slow down the pace of conversation. And because allowing for people who are using a communication device to actually express themselves, and then be listening to other people, and then to be able to formulate their own responses, instead of continuing to move the conversation without their participation.

>> Shelly Christensen: Thank you Ann. And I -- we have to end right now because we have another webinar from RespectAbility coming up at half past the hour. So on behalf of the AAIDD Religion and Spirituality Interest Network, and the Technology Network, and the Faith Inclusion and Belonging department at RespectAbility, I want to thank you all for attending the webinar series. Shea, Anne, and Rabbi Cook thank you so much for an incredible presentation. And again, everyone who's here and everyone who registered will be getting a copy of -- or will be getting the link to this presentation -- as well as a survey, which I hope you'll complete. So thank you, enjoy the rest of your day. Bye for now.