

TRANSCRIPT - STARTING A FUTURE PLAN FOR YOUR LOVED ONE
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>> Well, good morning. And welcome to Starting a Future Plan for your Loved One presented by Emily Braman of the Arc Oregon and Liz Mahar of the Arc United States and hosted by us by The Arc Oregon.

Thank you for joining us today for the live broadcast on December 18th, 2019. My name is Alan Lytle and I'll be serving as your behind-the-scenes host.

Today is being live captioned and a link to view the captions is posted in the chat. A recording of today's webinar will be posted later today at thearcoregon.org and emailed to all attendees.

The Arc Oregon has just celebrated its 65th year advocating with and on behalf of Oregonians with intellectual and developmental disabilities, or I/DD and their family. If you're new to the Arc or getting reacquainted with us, please visit us at TheArcOregon.org to learn more about our services or to find a local chapter near you.

Now our speakers today are Emily Braman and Liz Mahar. Emily Braman has worked specifically for helping people with disabilities for almost 20 years. Since 2018 she's worked for The Arc Oregon as program director for our guardianship advocacy and planning services program. Through her varied experiences as well as being a parent to a preteen experiencing I/DD, she has become passionate about helping individuals create and live

the life they desire.

Emily is joined by Liz Mahar Director of Family and Sibling Initiatives for The Arc of the United States. Emily and Liz have prepared a handout to accompany the webinar today. Look for a link in your control panel to download the handout.

I want to take a moment before we start to orient you to the go to panel. Take a time for look at the panel. If you're watching the webinar live it will be near the right side or top of your screen. Explore that control panel to see what options you have. Look for the question box. And feel free to submit questions there any time during today's broadcast.

We'll have time at the end for Emily and Liz to respond to the questions that you've submitted. Once you're done oriented yourself to the webinar control panel you can click an arrow to minimize it. Just one final tip. You can resize the webinar broadcast screen to suit your preferences. Look for buttons to maximize or resize your webinar. Including the slide show or presenter camera window.

I'm happy now to turn the webinar over to Liz so she can get things going. Welcome Liz and thank you for presenting today.

>> Thank you Alan.

Hello everyone. My name is Liz Mahar. I am a Director of Family and Sibling Initiatives here at The Arc of the United States.

I am also a sibling. I have a younger sister her name is Crystal. She has Down's Syndrome and she's in her early 30s living at home in California where I'm originally from. So, this issue of future planning is near and dear to my heart. I've been now at the Arc for five and a half years now

and my work has always goes on supporting families, caregivers, people with I/DD on this topic. So I'm really excited to speak with you all today. So, just to provide a quick overview I know we're going to be providing you all with a lot of information. So, I just wanted to let you know that when we walk out today, please don't be overwhelmed, you have mine and Emily's contact information. We are resources here for you today. Again we're going to go through a lot of information but hopefully this is a good starter for you on where to go next.

So, today we're going to cover a little bit about why future planning is important. We're going to talk, Emily is going to talk more about how to start a future plan. We want you to understand the core elements of future planning which should be included in the a plan and Emily is going to talk a little more also about resources in Oregon to help assist you in your planning.

Then we're going to end with doing a walk through of The Arc Center for Future Planning website and resources. I'm going to take you through our website and our build your plan tool, which is the tool that you can use online, it's free, you can open an account for free, and start a future plan. So I'm going to be talking you through those resources, so hopefully once you get all the information today, you can start a plan for your loved one.

So for those of you who are not familiar with The Arc, The Arc has been around now for almost 70 years. The national office. Our network. We have over 600 chapters all around the country. And what I like to say is when you've met one chapter of the Arc, you've met one chapter of the

Arc. All of our chapters started as a grass roots focus. It's very grass roots focus to this day.

By that I mean, when people started chapters on the local or state level, they started them in response to making sure that their loved ones had the resources and services to lead a full and independent life in the community. So some of our chapters through the state are more focused on advocacy services, so providing more information to families. And then other chapters are more focused on providing services, such as state programs, some of them run group homes, guardianship programs. So, we have a mixed sort of make up of our chapters and that's the beauty of the Arc today is that our chapters are all making sure they are providing the services that they need on the local and state level that the community needs.

In Oregon, we have around nine chapters around the country, around the state. And then there is some more information that you can visit. As Alan mentioned earlier in the presentation, The Arc Oregon is now celebrating 65 years. So we have a strong network in Oregon and we're always proud to partner with our chapters in Oregon.

So, what is future planning? You know, just to make sure that everyone is working off of the same definition about future planning. Future planning is essentially creating a guide for a person with a disability to make sure that they're leading a good and independent life.

A plan should be made, you know, at birth. We all need plans. And so, the hope is that the plan, that there is some plan in place throughout all stages of life, but it's especially important after the parent or

caregiver is no longer able to provide the level of support that they're providing to their loved one.

The plan is meant to be sort of a blueprint of the person's life so that way when the caregiver can no longer provide that level of support that they are providing, another caregiver, friend, supporter, can then pick up and help the person make sure that they are leading the independent and happy life that they've mapped out for themselves and have mapped out with their family and friends.

So, I know this is an online webinar, but we want to make sure that we are interactive and try to be as interactive as possible. So, I just want to give you all about a minute or two to answer this question that we have outlined here. And the question that we're asking you here is what are the barriers or challenges you face when planning for the future of your family member with a disability?

So, most of you should have access in the control panel to a question section. If you want to type out your response in that part of the control panel, we'll give you about a minute or two to think about that and to provide a response. And then I will then sort of read out some responses that we have received.

So, we'll give everyone about a minute or two.

All right. So I know I just gave you all a couple minutes, but again, if you have any responses to this question, we would love to see your responses. Feel free to type them in the question box. The question is what are the barriers or challenges you face when planning for the future for your family member with a disability?

Response that we got here was, lack of natural supports. People that are willing or able to step into the role. Finding a good environment in another home in the state of Oregon.

Another one that I'll throw out there is there is just a lot of information out there. And what you don't know, you don't know.

So I appreciate folks who have provided responses and please feel free to continue providing responses as we go throughout the webinar.

I'm going to move on to the next slide just for the interest of time.

So, you know, barriers to future planning, just to provide with you a quick overview. You know I'm sure a lot of you when you see the slide are nodding in your head right now in agreement. We have nearly a million families in the US where there is an adult with I/DD living with an aging family member and there is no plan in place for that person's future. Then there are a lot of barriers that they're facing that could discourage future planning. And these are some barriers that you might be experiences.

Like I mentioned the lack of information. You don't know what you don't know. Where to find information, information that's truth worthy.

Addressing emotional issues relating to the caregivers mortality. No one wants to think about the time when they're no longer able to provide the support for their loved one.

Unavailability of appropriate service or distrust of the service system.

I know in my family, when my sister was born, her doctor recommended to my parents that she be put in an, put away in an institution. And because of that, my parents besides public school never accessed services formally which means she didn't get any early intervention and she wasn't connected

to the service system in California until she was in her will late teens, early 20s. And that all came out of one bad experience with a doctor when she was born.

Then, difficulty of affording services of attorneys and other professionals. We're going to provide you today with a lot of resources that do not cost money. And I know there are times when you are going to need an attorney, but just because right now you might be sitting and saying, well you know, I got to do this thing that's going to require an estate planner or other type of professional. There are other things that you can be doing in the planning that doesn't require paying for services. So, we want to make sure that you are fully aware of what The Arc has to offer, not only on a national level but in the state of Oregon to help you.

I'm going to pass it back to Emily so she can provide an overview of the core areas of planning and resources in Oregon to help you with that.

>> Good afternoon. I am Emily Braman, and I'm glad to be here with you today. I'm going to start and really spend most of my time talking about seven core areas that you should really look into and have some discussions and conversations among your family and with your loved one in the terms of creating this future plan and getting it in writing. So I'm going to one, go over the core areas and then for each core area I'm going to give you a brief list of some Oregon resources.

Keep in mind that these, when they come up on the screen, there will be links but they're also included in your handouts, so you don't need to be quickly scrambling to write all the links down.

But yeah, excited to get started. One thing to know about future planning too is that part of it is writing down what's going on now to make sure that can continue, particularly in these areas. And then also planning for when the caregiver is no longer able to care what you want happen. Because some of the things you're doing now or life experiences are vital to quality of life for your loved one and you want to make sure those don't disappear over time.

Another vital aspect besides these seven areas in terms of planning with your loved one is making sure you include the individual who you're planning about, to the extent that they can participate. It is a life plan or future plan about them. And so, however they can participate and be involved and drive that discussion, it's more person centered and it's more focused on them and they'll be more invested in wanting to participate in it.

One example is, I used to provide support for a young lady who was nonverbal and used minimal sign and didn't communicate much, but in terms of planning for her future, one thing to make sure to get written down and really understand, was the aspect of food in her every day life. She loved food. And so one thing in planning for her and that would go maybe in the health and wellness or expressing wishes for the future, what foods were really important for her around Christmas or Thanksgiving that really meant that holiday was there. So some of those traditions. So that was a way to involve her even though she didn't talk and say exactly what she wanted, but you knew those were important and would help her going forth. So, our first area is expressing wishes for the future. Some things to

consider is there is multiple perspectives and opinions going on. Like I talked about. There is the individual whose life this is, but there is also you as caregiver or mom, dad, sibling, what do you see for the future? What do you want your role to be? And how would you like to see this, how would you like to see your loved one's life to continue to go on?

So, just remembering to connect with those important people in the individual's life as well as the individual.

Also developing, if you know what a person-centered plan is and really focusing on that person and what is important to them. And as I said before, a key thing, especially in expressing wishes for the future is that information gathering or sharing of values and beliefs.

There are things, especially in this season that we're in right now, that we all hold dear in those traditions. We all, like that is just part of the season. Getting that down on paper, so that when you as the caregiver are no longer able to provide care, your loved one can still go for a drive and get hot chocolate and look at the holiday lights, or can go and maybe you always watched the same holiday movie. But getting that stuff down in writing so that as care transitions to someone else, those key pieces that make up who we are really continue to happen.

There are some resources for that through the Oregon training and consultation OTAC. Also the Oregon advocacy is a great resource to help people with disabilities in terms of directing and knowing what they want for life and getting it down. As well as here in Oregon we're using what's called charting the life course. So you may hear that verbiage more. So

those are things that you might want to look at in terms of expressing wishes for the future.

If you notice my icon there is a little notebook. That's to remind me and to let you know that it's really important to get all this information in one place, so that if the transition has to happen quickly with you not able to provide care, the information is all there and nobody has to go looking and gathering and searching through files. That they can just pull it up and right away be able to support your loved one in a very smooth transition.

Our next one, and one that is really big for a lot of people is deciding where to live. This is usually a conversation that sometimes almost starts happening from birth for families, about whereas an adult or where when the primary caregiver is gone, is my loved one going to be living and how are they going to be supported.

There is a lot to it. There needs to be conversations, one, with the individual. Where do you want to live? What does that look like?

I once supported a young man who was the youngest of three siblings. Older sister number one grew up, moved out of the house. Older sister number two, grew up, became an adult and moved out of the house. And then he grew up, graduated high school and was still at home. And even though he did not use verbal communication, he made it very clear that his desire was not to continue to stay at home to live. And he ended up moving into a foster care home and thriving. But he had watched his siblings grow up and move out, and that's the next step and he was ready to go.

So, what does that look like for your loved one and how can they get those

support needs addressed?

A big one I know here in Oregon for all of us is finding that housing. Are there apartments available? What do, how do group homes or foster care homes work and what do they look like here in Oregon? Along with financing the housing.

And so in some situations, you know, is from Section 8 housing, or if your loved one is living in a formal residential services it's called in a group home or foster care, then it's usually paid for through their Medicaid. So, understanding the different structures for how those can be paid for, and what it looks like to set those up.

There is also, in Oregon, I'll go to resources. Some resources for saving, to purchase a house.

So, one of the things for housing in Oregon is contacting what's called your community developmental disability program for housing options. That's usually what people called D D services, developmental disability services. They're the ones that have a lot of contact information for finding housing, particularly if your loved one is needing housing in a residential setting like a group home or foster care.

Oregon also has housing voucher programs. And we have an agency called community vision here in Oregon, that does a lot to help individuals afford their own home. They have saving programs, savings programs where people can start to save for a downpayment and get matching funds.

So, they are a great agency to look into for this.

Another one that goes straight with housing and is usually at the top of someone's list is how to finance the future. So, besides how to finance

the housing, how do we finance the activities of life. Many of our folks, if not all, are, use Social Security for income. And what does it look like to have funds available for them to be able to pay for everything? One of the things to really think about when you're looking at financing the future, is accessing maybe some of the public benefits that you haven't accessed as your loved one has lived with you. So, looking at your local self sufficiency office and seeing if your loved one qualifies for snap, which is our food program here in Oregon.

Looking and see if you don't have your loved one enrolled in Medicaid, if they can qualify for Medicaid or the Oregon health plan, but really looking at what are those services available that maybe you haven't accessed that could help with financing.

Also included in that would be, if your loved one has excess funds do you need to look at a special needs trust or a pooled trust? Because with Medicaid and with Social Security, or with Social Security, your loved one can only have two thousand dollars in assets at a time. And so, if they have more than that, or if you're wanting to leave them some money, determining if, what type of trust or savings account would work so that it's not counted as a re source, so they can continue to be eligible for Medicaid.

Also with special needs trust, and I know this is a pretty high overview of some of this, but there is also now in Oregon called the Oregon able savings account. And it's another way to save money that's protected so that your loved one's Social Security benefits and Medicaid are not at risk.

This is one area where a lot of families look into and see if they need to consult a professional. Establishing a special needs trust and making sure it meets all the requirements so that the money is protected, is usually best done through an attorney or a financial planner.

With pooled trusts, they usually, the pooled trust has someone you can talk to and find out if that's what is best.

Another one, and it comes to a concern that was brought up in our questions, is, identifying who that person is that can manage funds after you're gone. Do you have a family member, a loved one, a friend, that can do it; or so you know, there are professionals who can assist in had that. So there are, with Social Security, there is what's called representative payee, which I'm sure many of you know about, but there is also agencies that provide professional representative payee support and so if you can't find a loved one or a family member to do it, there is that option. And there is also people who will, professionals who will manage a trust for you. Or, if you use a pooled trust, many times those have a trust manager who would then be able to manage it for you, so you wouldn't have to find an outside person within your circle to manage it.

Resources within Oregon, like I talked about, your county self sufficiency office is one way to access many of these. In particular, the supplemental nutritional assistance program or snap. We also put on there, the Oregon able savings account and the Oregon special needs trust.

Another resource for you here in Oregon in regards to benefits and Social Security is there are what are called benefit specialists that help individuals with disabilities with questions related to their Medicaid,

Social Security, health insurance and help work through some of those barriers. And that's a state program here in Oregon, and the link is mentioned there.

But there is someone who can come in, particularly if someone starts working and you're worried about income, they can help them navigate that and make sure they understand what that looks like.

I was going to say, one more thing within that -- sorry, getting ahead of myself.

The next area and one that sometimes not so much as the supporting daily decisions, but we've also combined it with supporting major life decisions.

In Oregon, two methods for supporting daily and major life decisions, one is something called supported decision making. It's making more of an impact in Oregon right now. And it's just supporting people who experience disability, to make the decisions they need in their lives. Just like if I'm going to go purchase a new car, I would go maybe talk to my dad, because he was a CPA and he manages money and he could help me know what kind of loan I might need, how that would impact me. Or, I have a stepmother who is a retired pediatrician, if one of my kids get sick, I call her for advice.

But it's a way of setting up a place for people with disabilities they can rely on other people to help them make a decision and then the individual makes the decision instead of someone having to make it for them.

And then there is guardianship; which guardianship is a legal decision

making structure that is done through the court system. And in Oregon, it is not easy to not go through an attorney. In Oregon, most people go and utilize an attorney to get guardianship. Just because it is a complicated process and has a lot of steps.

But other areas to consider with major and daily decisions is how does your loved one communicate? How do they relay what is important to them? And how can you make, let others know this?

So, I support a young lady who the answer to every question is no at first. So, if a new caregiver was coming in, they would think she doesn't want to do anything. She doesn't like anything. And what they need to know and what I need to write down for this future plan and for supporting her, is that give her a couple seconds. If she says no, look at her and just wait and in a few minutes, she will give you the answer that she actually thinks.

So, there is informal support. There is apps. The iPad has come out and brought a lot of freedom and way to communicate with people. And a lot of way to relay how they want their daily support and just what our daily decisions and what that looks like.

In terms of formal, more formal support within major life decisions, I talked about representative payees already and that's for Social Security money and that is a person who can change over time. So, if you as the primary caregiver are representative payee, and you're no longer able to do it, somebody else can come alongside, whether it's a family member you know, like I said professionals do offer the service. And then if your loved one in their future plan, if you looked and decided maybe a group

home or foster care is where they're going to need to be supported, many of those providers provide representative payee support.

In Oregon, we also have the advanced directives, where someone can outline how they want end of life care provided to them. And appoint a health care representative for them.

There is also Power of Attorney for financial decisions. And then in, there is guardianship. And I do point out, in Oregon, guardianship is looked at as a last result. We have changed how we petition the court. So if you are a guardian or if you're looking to support your loved one through guardianship, you do need to know that in the petition now, what you submit to the court, you do have to express what other options you have tried that didn't work.

So, that's something you could work with either, like your developmental disability services coordinator with. Or if you're working with an attorney for the guardianship, what those would be. But some of those least restrictive alternatives, or alternatives are the representative payee, advanced directives. But that is new in Oregon.

Some supports for you regarding guardianship and then supported decision making in Oregon. We have here at the Arc a guardianship and advocacy planning services program.

There also in Oregon in five counties now but really spreading and trying to grow, is what's called guardian partners. And they offer a parent training or a new guardian training. So if you're a family member who becomes guardian, they offer a training on what that role looks like, so that you can really understand what your responsibilities are, and what

the parameters of your role as guardian are, so that you don't maybe overstep.

Also, disability rights Oregon has some great information on supported decision making and some of the other alternatives to guardianship, if you wanted to look at their information.

Another area to consider and one that's where you and I spend most of our days and most people is what does employment and daily activity look like for an individual? This is really what makes up who we are and what does your loved one want to do.

If they are employed, do they want it to continue and who are the key players in making that continue and go on? Who are those contacts? And what support is needed to continue to be employed?

And again, what are those daily activities? What are those things when your loved one is home with you, that they really enjoy or that you make sure to do, whether it is once or twice a year, a tradition around a holiday, or if it's like in my family, we have Sunday dinner at grandma's. And so, if that is something your loved one participates in, if it stopped it might cause distress, it would be something you want to relay and see if there is a way to continue that or something similar.

But what are those things that make it up? Or maybe every other Friday, they go to Sheri's with their best friend from high school. And so in any future planning you do, you want to make sure to write down which Sheri's that is, and what that friend's name and contact information is, in case your loved one isn't able to make those connections on their own. Because you wouldn't want that to disappear from their life, if it's been

something really important.

One self advocate wrote, particularly about daily activities, I wanted to join a bowling league and couldn't get in touch with a bowling alley. Then it turned out the bowling alley went out of business. Instead I decided to take square dance lessons which was the best thing I ever did. Because the minute I walked into that class, I knew that was the activity for me. I took lessons. I joined two clubs in the area. I met my husband. And that was four years ago in 2011.

So, what are those things your loved one enjoys? And maybe, if you don't know those, start exploring them so those are things that can continue once you're no longer able to provide support. So, starting to build their network of people they interact with, things they do, places they go. It really helps them to know that those, those things can continue. Their routine won't be changed.

One thing to really consider too with an employment and daily activities is what does transportation look like for your loved one? So, is it that you have live on a bus line, or are they dependent upon somebody driving them? And if they are, in that future plan, what does it look like for them to still be able to access those things? Are they maybe going to have to own a car and then have one of their support staff drive them? But what does that look like so that they can continue to enjoy those activities and not be restricted based on no transportation.

One of the big resources in Oregon for employment services is vocational rehab. Vocational rehab in Oregon has over the past few years really increased their service and support for people with disabilities, so you

see there is their intake line and questionnaire to get started.

All right. We've got two left to go. I know this is really quick, but these are things we really want to make sure you understand and know, just to consider and keep thinking about, because we want to make sure everybody in their future plan has multiple aspects covered, that it's not, those primary big two that everyone thinking of that are housing and financing, but these other parts that make up our lives are considered and really looked at.

What does social connections and social life look like for your loved ones? It's kind of similar to some of the stuff I was talking about in daily activities, but who are those friends? Who are those supporters? What are those groups they're a part of or those places they go where they're known? And making sure that they have strong connections with those, and that those are written down somewhere, so the next caregiver coming along can be like, oh, every Monday night, Sarah goes to this activity called drop in at the local rec center. It can be within your safe communities, it can be the local recreation center.

Another thing to look at is strengthening those connections with others and broadening your individual circle of who they know.

I was working on a future plan with a family that they had the finances in this order, they had housing in order. And they knew what they wanted, but they didn't have the people to make that happen. What they wanted is their loved one was going to stay in the home. They were leaving the house to their loved one. And they wanted a friend or a caregiver to move in and provide care for that individual, but didn't know how to go about

finding that person or what it would look like to find that person after they could no longer care for their loved one.

And I talked with them about, I know you like providing all the care for your loved one and knowing what's going on, but this may be time as you're starting to get a little older and needing more support, to bring in an outside caregiver, even a couple hours a week, so that you can start to see what it looks like to have a caregiver in the house. So your loved one can start seeing what it's like to get care by someone else. And building that relationship.

So I worked with them on that. And that it didn't have to be a caregiver coming in the house all the time for an extended period, but to kind of start that relationship and see how it would work and what it looked like, so that when that change came, it wouldn't be so drastic for their loved one, and they could get to know a couple caregivers and start building that relationship with them to see if that was the person that would be appropriate to take over.

So, that's one thing that family did.

Like I said, things to consider with your resources. One for social connections, there is your park and recreation district. Many of the bigger areas in Oregon, their park and recreation district have inclusion programs or what's called therapeutic rec programs. Targeted for individuals who experience disability in order to support them in park district activities, or your local recreation center. We do have in Oregon, some family networks.

I've provided the links there. And sometimes there is those disability

oriented or disability specific agencies. I've listed a couple here, but we have quite a few strong ones in Oregon that can help you and your loved ones start making those connections. And continue those connections so that they last after you can't provide care.

One more. I'll go through quick so we have time for the rest. Health and wellness.

Need to start talking about what that transition for health care looks like. If there is a designated health care advocate that can take over or patient navigators.

We have, like I said in Oregon, advanced directives that a person can appoint a health care representative. We have in the state of Oregon coming out next year what's called a health care advocate available through developmental disability systems services.

So, what does that health aspect look like? And then again, back to that notebook in the beginning, getting it all in one place, so that that next caregiver after you knows all those specialists that you coordinate with and knows all those medical supports you provide.

And besides just medical, there is also wellness, which is, you know, just taking care of ourselves, whether it's swimming, walking, social, but what does that look like for your loved one and getting it written down.

One thing I would love to share is through the Oregon health science university, they have some videos now for self advocates and families. It's a toolkit about what conversations to have about health care and how to help your loved one really understand what goes into their health care. So, we will make sure to get you that resource. But it's a brand new one

done through the Oregon self advocacy coalition and our Oregon Health Sciences university(indiscernible).

So, resources, you have Medicaid. There is also the DHS medical assistance. Like I've talked about, advance directives and POLST. Those are more directive in life, what does it look like toward the end for your loved one.

And these are the more wellness ones. We have Special Olympics, Mount Hood Kiwanis Camp and they are your local parks and recreation districts. Then if your loved one is a senior, there are a lot of senior centers that have activities that go on that they can participate in. And a lot of senior centers that provide meal services like Meals on Wheels.

Really quick, because this is one of the primary sources of resource here in Oregon, is your community developmental disability program. This is your developmental disability services coordinator, your local county program.

Services through them and support are free. And I'm hoping all of you are connected with them, because they are who can really set you up and help you with many of these planning areas, particularly with housing and how, and employment.

So, make sure you've connected with them. You know who they are. If you have more questions about them, I can answer those later. You can reach out to me.

Please know in Oregon, we also have what are called brokerages, so those living at home over the age of 18, you can also choose a brokerage to develop, to deliver your developmental disability services. They offer

much the same thing as your county support, but they're only available for folks living in a family home or on their own, not for folks who are in group home or foster care. And that's just how Oregon has set that up.

A quick link, if you don't know who your local developmental disability program is, this has been provided for you.

So, there was a really quick high overview of the have seven really key areas to start having some discussion about future planning with your loved one, with not just your loved one but their support circle as a whole and each of those key areas, what is it your family wants to relay, the individual wants to relay.

I'm going to hand it back over to Liz now, because she's going to show you The Arc Center for Future Planning and how it can help direct you through each of these seven areas and really get a plan firmed up and solid and in writing.

So, here is Liz.

>> Thank you Emily. And I am going to go through this pretty quickly again, but feel free to reach out to me if you have any questions about any of the information that I've covered today; but I really encourage everyone on the line today to visit futureplanning.dothearc.org, that's our site for future planning website.

The site was established a little over five years ago and our resources and all the information you see here today are meant to provide support to caregivers and people with disabilities. So you all on the line are the people that we want to serve. We want to serve your families.

So, I'm going to give you a quick overview of the website. Future planning at thearc.org. When you come to the website, I encourage you to visit our learn section. You'll get a quick overview only future planning, 101, so some questions to think about as you're developing your plans. And then some information about who to consider as part of your future planning team; whether it be family, trusted family members, friends. But also going outside of that circle of support in that person's life and see who else can serve on what we like to call the future planning team.

You'll see here a plain language document. We developed these plain language documents a couple years ago. We have an advisory council who are comprised of self advocates, caregivers, chapters of the Arc who always review our information. And so, we had some self advocates in chapters say, you know, you really should have language that some resources at a lower reading level.

So that's how we came about developing these plain language documents that we have here on different sections of the website. So this is a good 101 to, you know, kind of provide you a comprehensive overview of future planning.

The who are you section, that's meant to provide information to anyone who plays a role in that person's life.

So, for example, you might come here and let's say I'm a sibling. I am a sibling. So, when you click on the different sections there, you'll get an overview about your role in the future, in the person's life; on the future planning team. And then additional resources.

The chapter staff or again if you're a parent, it will provide some overview

and information about how to support you as you're going through the process.

Then the where to start? Everything that Emily went through today, is covered here. Not the Oregon specific information, but sort of going through all of the different areas of planning, so it's more of a high level overview on that specific topic.

So, on each page, that covers a certain topic. We provide information that you should consider. There is also a video in each section. So, this is, these are videos that we developed with self advocates telling their stories. People with disabilities telling their stories about how they were able to achieve success in that certain area of planning.

So, in addition to the plain language documents that I mentioned, we also have videos because we know that people consume information in different ways.

Then we also have free webinars. We offer webinars through The Arc's national office. If you're curious to see what type of webinar subjects we've covered in the past; we have webinar archives for free.

We have a list of up coming webinars which looks like we haven't updated yet. But if you have any information, we have a contact us form on the website as well.

If you're looking to find resources, I know The Arc of Oregon has a plethora of resources, tons of resources, but if you're just curious to see what else is out there, we have resources in our directory here. We also have all the videos that I just showed you. We have those in a video gallery on the website. And it's the page is linked, is titled see how others

have planned. So you'll see all the videos that are sprinkled throughout the website in one web page.

Then we have urgent needs section, where if it's more of a crisis. I would highly recommend reaching out to Arc Oregon, but if you wanted to get some information about who to contact when you're in a pinch, we have an urgent need section.

We also have a new web page in Spanish. So, a lot of the materials we have, like the plain language documents, some other tip sheets that we've developed over the years that are located on our website, they're also all found here in Spanish.

So, we also have the build your plan tool that I mentioned. The build your plan tool is a way for you to create a plan online. You create an account for free. And what happens is, you'll be taken to that page, answer all these questions, and then set up the account.

And I already have an account, so I'm just going to log in.

Then you're taken to our build your plan section of the website, build your plan tool.

Then you will see the different areas of planning. We have not developed one for wellness health. We decided not to develop one for health just for a lot of privacy concerns. So, we focus more on the six core areas of planning.

So, I'm going to quick on the supporting daily and major life decisions. You can start anywhere you want. I would recommend starting in the expressing wishes for the future. But again, if right now the focus is making sure that the person has their supports as it relates to daily and

major life decisions, that's sort of your main focus right now, feel free to focus on that. But if you're kind of new to planning, then I would recommend starting with the expressing wishes for the future.

So, you'll see here, you will be, it takes about an hour to two hours to go through each section of the plan. You're asked questions, fill them in.

If you do in the have a response to them, when you click next, it will save the, what you've done so far, or it will save and add what you have yet to complete. And it will add it to a to-do list. So that way, you see the, here, let me go through this. To-do list. And you'll see a to-do list by each area of planning.

So, you can see here, I have a lot of, a lot to complete on my to-do list. But it's a nice way for you to organize what you have yet to have done in each area of planning.

Then you can also review your completed to dos.

If you want to view your plan, see the progress that you've made in each area, you can do that. And then if you want to share a plan with someone, that's my husband there, so I've been sharing portions of my sister's plan with him. And you can write the person's email, their name and include a message. And what it will do is send an email to that specific portion of the plan, and then the person is then taken to that specific area. They can view it. And then they can add comments to the plan.

There is no, for the sake of privacy and also to make sure that ten people aren't editing one plan, we included a comment section.

Then you're able to print your plan from the website. And then again,

if you're able to view plans that have been shared with you.

So, crystal is my sister. And this is the progress that we've made on her plan, which I promise we've made more progress, but we haven't included it online.

So, that's a very quick over view of the build your plan tool and The Arc's resources online. So I definitely encourage you to visit future planning .thearc.org. And really start to look around and see what's available. And then follow up with The Arc Oregon, with the information that they need.

So, with that I'll hand it back to Emily to close this out and to answer any questions that you might have.

>> Hello again. It looks like we probably only have time for one question, however we do have them all in writing here. And we will be able to reach out to those of you who we don't get to your questions individually. So, please, if we don't get to your question, don't worry it won't get answered. We are able to follow up with you.

So, Alan, would you like to guide us on questions?

>> Yes. A question from Tanya, Tanya asked how is future planning different when the person with a disability is under 18?

>> Well, there is two aspects that could go to that. One is you could still do future plan like we talked about and look at all these areas and start building it. I'm wondering if some of your question is, what happens if the individual is still under 18 when the primary caregiver can no longer provide care.

And that, you could set up the same way a parent does for a child who doesn't

experience disability, of looking to find a family member who might want to care for them and setting that up through estate planning with an attorney.

But you can always look at future planning for your loved one under 18 at any age and what does that look like and start learning and exploring those options.

One thing I didn't mention in daily and major life decisions, is decision making and decision making ability is a skill. So, for your child that is under 18, start really working with them on how to make choices and build that skill and build your understanding of how they relay information.

>> Excellent. Looks like that will be our last question for today.

Emily, any closing comments?

>> Liz and I just really want to thank you for tuning in and listening to this and participating. As we said before, we're both available for follow-up questions. You have our information on the screen for you right now.

And again, this is something she and I are both passionate about, being family members. And we just want to make sure folks have the tools they need so that they can put these elements in place to support their loved ones as they the caregiver ages or you the caregiver and as your loved one ages.

So, again, thank you. And please, at the end of this, if you could complete the survey. And again, feel free to reach out and for those of you there were a couple very specific questions in the question box and we will reach

out to you to follow up about those. So thank you very much.

>> Thank you Emily and Liz. And that brings us to the end of today's broadcast. If you have any more questions or you would like more support with any of these resources, please reach out to our presenters using the contact information we've provided on the hand out. An a copy of that hand out will be sent later today in a follow-up email to all participants. Now, as soon as the broadcast ends a brief survey will appear on your screen. Please take a moment to share your thoughts with us. Your feedback will help us improve future programs just like that.

Now on behalf of all of us here at The Arc Oregon we want to thank you for joining us in today's broadcast. Have a great day.

(End of webinar).