

SPIN Conference 2020 | Pathways to the Future Video Transcript

Okay. Welcome everybody! We will go ahead and get started to honor everyone's time today.

My name is Amanda Kaahanui and I'm with SPIN, and on behalf of my SPIN sister Susan over there, say hi Susan--there she is--and our amazing SPIN advisors we welcome you to our Saturday morning workshop for SPIN's Recipe for Success. Today we're talking about planning for transition.

So we are going to be starting our show here. Let me share my screen with you, and we'll do some morning announcements and housekeeping. Okay. All right.

There we go. All right, so this workshop will be recorded, just for you folks to know, and we will be captioning it and putting it on our website for later. So for viewing, okay?

We also want to remind you about some Golden Rules for having a great Zoom. So please stay muted. We are in a large meeting today and not a webinar, so please stay muted throughout the presentation. If you have questions you can type those into the chat box. You can leave your video on or off, and that's completely up to you, whatever your bandwidth can handle. Okay.

You can change your view options right up there on the top corner of your screen. So depending on how you want to see us. And we ask that in the chat box, when you're asking questions or making a comment, please be kind and considerate to one another and be respectful of our speakers.

We also want to let you know that the captions have been enabled, so Zoom is now doing live captions. They are A.I. so they're not always 100% accurate, but we want to let you know that we will be captioning this recording and putting it up on the website for accessibility.

So not to worry about that. But if you want to get the captions today, just look down in the black bar on the bottom of your screen where it says "cc live transcript" hit that little up arrow and you'll see the thing that says show subtitle. And if the captions are bothering you, you can turn them off the same way, and just say "hide subtitles."

We want to remind you, as well, we have one more workshop in this small series. The next one will be on June 19th--Arriving at the Future--and we'll have some parents coming to talk about their story along with their youth. And I have to share with you as a parent, parent-to-parent support and story sharing is one of the most important things that we can do for one another as parents. It helps us feel like we're not alone, but also we learn tips and tricks. So it doesn't matter if you're an older parent sharing down information.

It doesn't... or if you're a younger parent, kind of gleaning that connection with one another is super important. So we hope that you'll join us for the June 19th workshop. We also want to remind you that SPIN has two websites now. We have our original website-- spinhawaii.org-- that's where you're going to find the Parent Guide and our resource guides. Our newsletters are there. Our calendar is there, and our amazing infographics. And then we have a new SPIN Conference website, and that's where our October workshops from our conference in October 2020 are. And that's where these workshops will

also be situated. So if you want to come back and watch it later, download any of the handouts or the presentation, they're all going to be on that spinconference.org site.

We cannot do this without our advisors. Susan and I are a two-person SPIN team, and so we rely on our SPIN advisors to help us plan the workshops, the topics, speakers--everything! And a few of them are here today on their Saturday morning helping us with this workshop, so thank you all to our SPIN advisors. And we want to remind you to stay tuned after the Q and A session today, We have two \$25 gift cards that we would like to give away. You must be present to win, so please stay tuned after, and we'll call your name, okay? Hopefully we'll call your name.

Before we get started, we do have a poll. We'd like to get a little more information from you. So let me just see if I can run that poll for you. And if I can get one of our advisors in the chat, just to let me know you can see the poll, because I don't see it on my main computer here.

Great! We can see it. So if you can go ahead and just tell us who's here. Are you a parent? caregiver? teacher? other professional? Are you a student or a self-advocate?

Where do you live--what island are you on? The great thing about Zoom is that you can be on any island. You don't have to worry about being flown

over. It's amazing! We also would ask how old your child is? These workshops are appropriate for all ages of students. We don't just start planning our kid's future when they get to high school. We're thinking about this through their whole life.

So these are going to be good skills and tools you're going to be learning today.

So we're super happy to see some of our younger families here today. And then we also want to know, if you've ever learned any life planning tools. So just go ahead and answer those few, four questions we have in there. We'll give just a couple of more minutes for folks to jump on.

But this will help also our speakers today understand who's in the room with us.

Okay I'll go ahead and end the poll and share our results. So we have a lot of parents here today and some other professionals. Thank you for joining us. We're so happy to see you. We've got Oahu and Maui represented today, and we have kids from elementary, middle school, high school, recently transitioned, and adults today. That's awesome! Nice mix. And we have some folks that have used LifeCourse, our life planning tools, but a lot

of folks haven't. And some is "what the heck is a life planning tool?" So don't worry. We are going to get to that today. Okay. All right. So hopefully my poll went away. There we go. And without further ado, let's go ahead and introduce our speakers today. We are so excited we have five dynamic presenters for you. We are going to start off today with Tricia and Pat Sheehey. They're from the UH College of Education, and they're also parents. And they'll be sharing some wonderful information for you. And then we also have Abi George-- Abigail. She's from the DDD. That's the Division of... Developmental Disability Division. And she's going to be sharing some planning tools.

And then we have our lovely parent/youth duo, Michelle and Renee Manfredi. And they're going to be sharing some of their experiences using these tools. All right. So let me go ahead and stop sharing. I'm going to put myself on mute, and I'm gonna say Pat and Tricia, you can take it away.

Okay, here we are. Ready to start. I hope everyone can hear. If you cannot hear me, please let me know--thumbs up or something. So I can see, I see some of you on my screen. Thank you.

Thank you. I appreciate that. All right. So when Susan talked to me about doing this presentation, and she mentioned skills through for a marathon, I went, oh boy! I know a little bit about that.

So back in the day when Susan talked to me about this, I thought to myself, hmm... this is interesting. I've actually run two marathons. And then I thought, no, I've run three. The first marathon was when I gave birth.

Labor was a marathon. Any of you who've gone through labor know it's a marathon. And then I did run the... a marathon, and I think it was 2002.

The Honolulu Marathon. And then the third marathon actually started in 1976 and that was a marathon that lasted 28, over 28 years. And that was the marathon we ran, my husband and I ran together, with our son Tom who was born in 1976 and passed away in 2005. I've thought, I really thought about what was it that I needed in order to run a marathon. When we had Tom, I had no idea what I needed in order to survive and run this race with a child with a disability.

When I was planning for my labor I did a lot of planning. We went to classes. We got books. We read. When I was running, gonna run the Honolulu Marathon, I did the same thing. I read books. I talked to people who had run marathons. A couple of my brothers had run marathons, but I really took it to heart, and I found out what I needed to do. But I wondered how did I get through those 28 years with our son Tom and all of the potholes, and all of the bumps in the road without some skills. Because I really didn't, we didn't plan this, and so I went back to what did I need when I was running my marathon? And one of the first things I needed was I needed training. I needed a plan. And so

my suggestion for anybody, is when you have your child, you develop a plan, a plan of action. How am I, what do I need to get through this? Whether you write it down, I would say writing it down, but getting together the resources that you need in order to survive however much time and all of the things that are going to occur that you have no idea within that lifespan of your child that you're gonna need.

The other thing I noticed that I needed when I was running marathons was that I needed motivation. I had to have something to keep me motivated. Now you think that your child alone is motivation, and it's true. Your child is motivating. My child was motivating, but there were times when I wanted to give up. That I thought this, there isn't enough for motivation. Now one of the things we're going to look at as we go through this presentation is some of the marathon skills that are on a handout that you'll get that the Turnbills actually developed. And Susan got information from. And those, some of those skills are knowing yourself and your family. So part of motivation was knowing who I am and what I need. What are my strengths? What are my needs?

Another part of motivation was involved support. And my support came with my family. It came from family members who I had. A daughter who was going to run with me. But mostly my motivation in actually succeeding and running the 26.2 miles of a marathon was knowing that I visualized,

I visualized my son running with me. He was still alive at that time. He had, he never walked. He could, he never learned to walk. He's in a wheelchair his entire life, and I visualized him running next to me and holding my hand, and telling me, "mom you can do this, you can do this." So that motivation is really important and these other skills of that we're going to go through will help you see that they all are intertwined. They all mix together.

So more like a Venn diagram. I needed strength. How was I going to get strength? And as a parent, you know, you need strength. You need to endure through this whole thing. You need your strength.

So I found that I had to work out with weights. I had to practice running every day. And it's the same thing. Every day you build your strength, so that you can survive. So that you will be there.

You can go over those bumps in the road. You can climb those hills that have, that occur. And you can also get out of the potholes. And you're not going to fall entirely down and get hurt.

You can do this. And the last kind of characteristic, I guess, or skill or something, that I felt I needed was endurance. I needed to be able to see this through to the end.

26.2 miles. I had never run 26.2 miles. The most I'd probably run was two or three, but the endurance I built up over time. Each run I had I was successful. And then that put me to another, another space where I could run a little bit further, and go a little bit further.

And so there was, this is the same thing when you when you're going through life and all those transitions that you have in life that you think with your child are challenging. Yes they are, but you use these skills that we're going to be going over in just a few minutes. You use, you get to know who you are--what are my strengths? What are my needs? What are the resources? Who are the resources I can count on, and what are actual resources that I need. I'm not just people, but other things that I might need like a good pair of running shoes and being flexible. What is it that I need? I know that I can't do this myself, because my plan may not, I may have to change it a little bit. I may be sick one day. I may have a little injury. Something, things always come up, and I need to be flexible. I need to have a sense of humor. I need to find times when I can smile and get over some of the, just the being just

really strict and stern about I've got to do this. I got to do this. And take it easy and laugh and relax some. And so, those are the skills that I found that I needed in running a marathon. And not only the marathon, 26.2 miles. And not only a marathon of going through all the way through labor, but also a marathon of having a child with a disability and being able to survive all those different transitions in life that occur.

One of the items that is mentioned by the Turnbulls is the idea of knowing yourself and your family. And speaking both as a parent... and then I noticed that when the survey was conducted, there were no teachers listed there. But all of us are teachers—as parents one, but two when I add up, I taught, I probably taught both in special ed and general ed more than 50 years altogether. So I have a lot of background from that. And that idea of getting to know your family starts with yourself in your own

family, but it also, when you get to know your family and you present your family, it's not just the child that a teacher is dealing with.

You... that child is part of the family from which he comes, so it's important as a teacher that you get to know that family, and that you get to understand what their needs are.

And one way you can do that is by developing a plan of action, so to speak, basing it on the needs of the child, but initially based on the needs of a family. If you've, if you have a child who has a disability and that child was born with that disability, you might have been involved in some sort of family planning to provide some guides for you to follow in those first pivotal years of life. It's hard to look at a mirror to take a marathon mode, when your child is born, and the cardiologist says that he has about a 10% chance of living through the first year of his life.

It's hard to think marathon mode. So it shows you that one, doctors don't know everything, and two, that you better plan. Don't plan for your child passing away when in fact they may survive.

Another idea that the Turnbull's mentioned, by the way, is the idea of total acceptance of your child, and you'll see in this picture, in the picture here, that we had no idea that we'd have most of the people there are somehow related to us.

We ended up with a lot of kids, and we had no idea when we had Tom that we'd have so many. You can go in, and if you notice in this picture, the older young adults or they are men actually are looking.

We're at a restaurant, and so I put this picture, because it's knowing yourself and your family.

All those boys in that picture are looking at a sporting event that's occurring on a TV there.

So we're there for family time, but part of that knowing yourself and our family is knowing that, okay, these boys, they're brothers there, but they're looking at this TV, because this is more interesting. That's okay. It's okay for them to be looking at the TV at this time.

There's another photo where they're all over their brother. Oh, that's the only thing with this. So we talked about the MAPS meeting or the person-centered planning where you really get to know the child and the family's strengths.

Share that. Be honest and open. When you're going through transitions, that's a perfect time to have some kind of a person-centered planning meeting.

This picture shows Tom, and he's at the wedding of one of our kids.

And we always wanted Tom to be treated just like a normal kid. We treated him that way.

His brothers and sisters treated him that way. And we wanted other people to treat him that same way.

And so you see him here. He's got a... it looks like a Bud Lite glass or something, but actually he doesn't have beer in there. He wasn't that, we didn't want to be that part of it family. So, but he was included. He was dressed up for the wedding. He sat with the rest of the kids, and we felt good about that in terms of a dream for us, for Tom. Just the fact that he would live each day was... each day that he would wake up, and we'd go in and see him, he'd still be alive.

That was a fulfillment of a dream. Not all of you have children in that regard, but if you have a child with a disability, that might be a reality that you need to think about.

Okay. But also, even if it's not, you want your child to get through school to have an adult life, too. And we also have a daughter with learning disabilities. And that was what all we wanted was for him to graduate from high school, get out of school and then find something that you can do that's you like doing. And that was actually more of a challenge, those meetings that we had, the transitions that we had, was more of a challenge, because although there wasn't a lot for Tom as far as adult services at that time. Now with this, with that daughter, she's 25 or so now and she's living on her own with her boyfriend.

It was even more challenging, because there were, there was very limited resources for her it seemed like. And she didn't do that well in school. She did okay. So those were the challenges. And that's where I thought, if I had more, if I'd really used my marathon plan at that time, maybe we would have advocated differently for her than we did.

So the network. So this is the picture you see where every... the boys who are looking at the at the game are now looking at, they're all the camera, they're looking at the camera, but if you notice there's one that's holding on the wheelchair. That's Sean. He's now in medical school, and so he's actually almost done with medical school. So he, they all were a support for Tom in some way. Sean was the medical one when Tom had his seizures, it didn't bother him one bit.

Rory, the one you can't really see, he's in the back standing up with the dark shirt on. He came home from school when we were at Pahoia and we were, he was at Pahoia High School. Tom was an adult in adult services, and we were able to get on the waiver program.

Rory said he would come home during his lunch hour to change him, and now that was hard, because the school didn't want him coming home, but fortunately, we had an advocate at the school who said this is what ohana is. This is what Pahoia is.

This is family. They need this. His parents are working. They need this, so we need to allow him to leave campus to go home to change his brother.

Because at that time my mom was watching him, and my mom was in a wheelchair also, and so anyways, each member of the family really contributed and supported us. Here they are as youngsters you know, but you see they were close, you know. Tom was always included, and they were always there to support him. And even now they support him, and they support us. When it's the anniversary of his birthday, we all have McDonald's, because Tom loved McDonald's, and he would not eat cold fries.

They had to be hot, so when you live in Pahoia back in the early 2000's there, we didn't, the closest McDonald's was in Keau. That was at least a 20-minute drive. It was hard to get them back in time. So and then family, and then friends.

So we had a lot of friends and community members who were very, very close to us and were a wealth of support. They watched Tom. They provided, they attended meetings with us. We also had this gal down at the bottom here who's with Tom in the sand. We're camping. Turned

out she was probably about what, 13, 14?

She now has a child with autism who's, and it's interesting when you think back, and how loving and caring, and she knew. And she's a fantastic advocate for her child with autism, and she knows what to do. And we saw her just last summer with her child, with her daughter, and she's very interactive with her and allowing. And then there's professionals.

Now don't look at all these pictures, because let me tell you, there were things that professionals were doing back in the day that I look back on now, and I just cringe. And even at that time, looking at why are they having them put a round peg in a round peg hole. That wasn't, that wasn't a life skill he needed to learn.

But it's what the OTs did back in those days.

But they did a lot of good things. They took him to the pool to understand we had to advocate for that. That was something in high school that they didn't, they weren't going to allow, because he still wore diapers. He was time trained, but they said we can't go in the pool, because he still has a diaper. I said no, he's time trained, so we had to fight for that. And that was again in high school, and we had to fight always, especially in the transitions in high school, because there really weren't any adult services for him, but we wanted him to learn things that he could, he'd be able to do when he got out to experience.

Okay. And then another skill that the Turnbulls suggested for completing this marathon is to learn to be flexible. That if you're not flexible, then you need to know that, yes, you want something. You desperately want it.

Especially when you're planning for transitions you want this for your child. We wanted Tom...

We did not want him in an adult daycare. He would drive those people absolutely batty, and yet that's what they wanted for him. We did not want him far away. They wanted to bus him all the way into Hilo. That would have been almost a 45 hour bus ride. 45 minutes, sorry. That's right. So but we knew that we had to be flexible. There were only certain services that were available.

And fortunately the Waiver program came in, and we were able to say, oh great. We can have somebody come to our house. We hadn't even thought about that at the time, and so that really, really helped. But we were open to that when it did come.

This is, this is something I say to all my kids all the time: you can't always get what you want, but if you try sometimes, you might find you get what you need. And sometimes those things that I really thought I wanted, a year later I looked back, and I said you know what? I didn't really need that. I got what I needed, which was with the Waiver program. It was Tom being at home, we have been able to hire somebody as his personal care assistant, and creating an environment at home that was conducive for Tom. That was good for Tom. They used to lift weights together.

He'd take him out on the golf course, you know. He got Tom was an outside kid, and he loved all of those activities. If you don't have a good team that worked together... where there's respect, there's good communication, honesty, trust, then none of this is gonna work.

So you can have the best laid plans, but if these attributes of a team have not been developed, or if you find that there's something missing, really it's so important to go and try and do some decision making. See how can we fix this. What do we need to do to fix this? And we had to do some things to fix, to fix some teams that we had. And honesty, it's hard, but at the time it's... you're not calling somebody out but you're just talking about what you, what you need, what your strengths are.

I can do this, but what this team really needs is, you know, something. So part of it is that we were involved in... two minutes, okay... we were involved in so many IEP meetings for Tom. And the other thing is, I was involved in so many IEP meetings for students that I taught. Where is, if you don't have that teacher aware of your situation totally as a family, and you don't, and that teacher is not aware of what your needs are, and that those needs would be represented in the IEP, that it's pretty tough. You're almost like fighting a losing battle. And as a teacher, you need to be an advocate for the student that you have. And it's difficult as a parent when you walk into an IEP meeting and you're introduced to doctor so-and-so or this is the therapist that's coming in. All these people, and they're all on one side of the table and there you are with your family and the rest of our kids who would come, would have to come for the meeting.

It's demeaning. It's... you're at a disadvantage and you don't want to be that way. You want to have the feeling, as if you have a group of people who are in it together. Okay.

And one of the kind of classes. So it's so important to take time for yourself to find the humor in things and to de-stress. So finding the humor, whatever it is that makes you laugh, develop those opportunities. Bring them in.

And even if it's something that you have to force yourself, get out and watch Laurel and Hardy. I don't know. Whatever it is that can make you laugh, but when you're having a tough day, find something that'll make you laugh.

For me it's music. For Tom it was Metallica. That would not have been my choice. Probably most of you don't even know who Metallica is. But it's heavy metal rock, right? And it would, oh it was not de-stressing for me, but for Tom it was. And so music for me, music when I'm running music. Whenever I'm in a bad mood, if I put music on, for certain that'll do it. And Pat, too. We put it on in the house loud, for exercise. Find time to exercise. Make sure you eat healthy. Find times to keep yourself, give yourself energy. And exercise, believe it or not, if you can do it... I once said I hate, I actually hate to run. I really do hate it, but it's reinforcing. I feel good after I run.

And so that's what keeps me going. And I once had somebody tell me, just say you're going to go for 10 minutes. You can go for 10 minutes, and I never stop at 10. I always went longer.

So even if it's walking. If it's whatever. Go for a short period of time, and then

I bet you'll find that you'll do more.

And then meditation. Time to relax. Time to reflect. For us, we had a whole group of people, because most of our friends were through our church, and they were so supportive of us.

But they also, we pray together. We would hold hands, and we'd pray for each other.

And it really, it's what got us through. That's what got us through everything. But I know other people have other ways, so. But make sure that you find that time, you make that time for that.

I had, and this is unbelievable, but when we both taught it... we both taught a Kau Elementary back in the day, back in the day. Before a meeting, before an IEP meeting for a particular student, we would, the group of us, there was a group of us, teachers we would actually pray for ourselves and for the parents before the meeting. I'm sure the administration did not know about that, but we had a strong faith group just even within our, the teachers there.

So when you do these things, I tell you, you can survive. And you will. And you'll be prepared for whatever meetings you have, whatever those hills you're going up. And you think I don't want to go up it. I don't want to do this. I can't do this. You can, and you will use those skills.

Susan's going to put them on or they're going to put them in the chat or somehow you'll have access to them. Choose the ones that you think. We chose ones that we that really touched us, but you can see that you know 26.2 miles is a long way, but it's nothing compared to what you're doing with your child. And finally Happy Mother's Day.

And I'll stop sharing. (to Pat) Did you want to say anything final? Sorry! I tend to do that.

You want to present with me? Oh you want to just sit by me while I do it all? Sorry.

All right. I'll mute myself now. Okay.

Thank you so much Pat and Tricia. We really appreciate your wisdom and your words today. If you notice that Susan put in an infographic about those marathon skills.

It's down in the chat. It says download, so if you click on it now, you'll be able to download it right into your computer.

Otherwise we will have them on our website, and the link is in the chat for you, as well. Okay.

Let's go ahead and move over to Abi from the DDD. Abi take it away.

All right. Good morning everybody! What an act to follow! Isn't that amazing.

Tricia and Pat, thank you for sharing your personal story in regards to supporting your son. And you know, what I feel like I need to start doing something with my life, right? I gotta start running. I gotta do something. But right. Building off of what Tricia and Pat were talking about, today what we're gonna do is we're going to talk about the

LifeCourse framework. When it comes to supporting our family members and when it comes to supporting our children, right? In regards to having a plan, there's different plans you can have, you know. Just like what they say: there's many ways to skin a potato, right? Have to be politically correct now, right? There's many ways to do things, and at the end of the day, as long as we make sure that everyone's vision for a good life is met. So for those of you folks who don't know me, my name is Abigail George. I hail from the Developmental Disabilities Division, but today what I'm here to present and what I'm here to talk about is to talk about a framework that DDD has been shifting towards or shifting with to support families a lot better, right? Just building off of what Tricia and Pat was saying, right? Over time, our field is change, and over time we want to make sure that the services and

supports that we provide to our families change with it. So today I have the honor of co-presenting with the Manfredis-- Michelle and Renee. But first I'm gonna go ahead and talk about what the LifeCourse framework is, and then they're gonna go ahead and take over and talk about how they utilize the LifeCourse framework for themselves. So just like what Amanda mentioned when we first logged on, right? It's the beauty of talking and gathering with other family members. It's very crucial that, you know, children, families with young children coming up learn the tricks and trades of lessons learned from the families who've been here before. So with this Supporting Families Framework, it's a framework that was actually created by families for families from a wingspread report back in 2011. This framework is mastered through the University of Missouri at Kansas City in Missouri, and in which what they did was they gathered that Community of Practice for state ID agencies to share how they can support families so much more. So thankfully, here in Hawaii, DDD, along with our partners at DD Council, is conjointly practicing in this Community of Practice nationwide. All right. So what on earth is this Supporting Families Framework? It always begins with the person in the middle surrounded by their family. When we're looking at their family and the family dynamics, there's different life domains that they need to take consider, that they need to consider. We're moving beyond just keeping them healthy and safe, but we want to make sure that they're fruitful and living in the community advocating for themselves.

When we support families, we support families in three different ways: either through goods and services, through discovery and navigation, and, last but not least, connecting and networking with other families. The support can also be found in different types of support, whether they're natural or paid supports, and we want to make sure that these supports and this integrated of supports is tracked on throughout the lifespan and always heading on a positive trajectory. So this framework is actually based off of 10 guiding principles. Unfortunately we don't have time to talk about all of the 10 today, but I'm going to specifically focus on three-- on how the supporting families framework supports all people, supports throughout the life stages, and shooting for a positive trajectory, and last but not least, talking about an integrated support system and integrated delivery of supports.

So right. Throughout supporting our children, throughout even this presentation, I'm constantly gonna go back to this question: what is a good life? And you know when we're talking about a good life, my good life looks a lot different than your good life, right? My good life does not include running a marathon, because I don't like to exercise, but right, everyone's good life is different, and that's the beauty of what life is. So when we are talking about the Supporting Families Framework we go back to who can have a good life? Did you know that nationally in 2015 4.9 million people in the United States had a developmental disability, but unfortunately, of the 4.9 million, only 25% of them were eligible to receive DD services.

The rest of the 75% was not known to the system.

Either they didn't know about these services, they weren't eligible, or specifically they just didn't want services from the state. But all together with the Supporting Families Framework, these guiding principles serve everybody with or without a disability. So let's go ahead and talk about the second guiding principle and these are the life stages and the trajectory. So throughout life, right, we always want to talk about what is a good life. And when we're talking about the trajectory, when we're talking about life stages, we want to always answer this question, what does a good life look like?

Realistically when we're shooting for that life trajectory, everything, always we want everything for the best.

We want to shoot for the sky. We want to make sure that our children have a positive life, but you know what? Sometimes negative experiences happen, and then it, our trajectory, goes down all together. When we look at planning, we always want it to go towards positive outcomes, but we never want it to go to things that are unwanted.

Always shooting for the good life throughout the lifespan. But as you know, life isn't always that upward trajectory. Life isn't always straight.

And even a marathon, right? A marathon-- you're never gonna run straight. There's always going to be hills and valleys and different turns, but realistically when we're looking at the trajectory, and just planning across our lives, and as well as our children's lives, right, sometimes there's a death. We celebrate with first jobs. Sometimes we're laid off. But at the end of the day, we want to make sure that we plan to be flexible, we plan to focus on these different life experiences, to always kind of auto correct and shoot for the sky. Shoot for a positive trajectory.

So with a LifeCourse framework, and just like with any planning system, whether we're using MAPS, whether we're using LifeCourse, whatever it is, we want to make sure that we think about life experiences good and bad to make sure that our children, as well of ours as well, as ourselves, have a positive trajectory across the lifespan, right? From baby to aging adult there's life experiences along the way, good and bad, that can help make a fruitful life.

Next we're going to talk about the Integrated Support Star. So what the Integrated Support Star is taking a look at, the different supports that are available in your life. So when we're talking about what is a good life, right? When we're talking about a good life for ourselves, as well as for our children, we want to know who or what can help me out there. Whether we have people in our lives. Whether we have different agencies.

We're always looking for help and support, whether we know it, or whether we like it or not, to help us live that fruitful life. So if we're going to be professional and use the official term, it's natural and paid supports, but I like to see it as realistically who's helping us. It's families and friends, agencies, and even organizations like SPIN that can help us gather together with amongst other families to kind of work through our vision for a good life, building off of what

Tricia was saying, right? She showed a picture of her son, and she wouldn't necessarily agree with the type of treatment he was receiving, but that's what services were like before, right? When we're looking at services and support, it constantly evolves. When we're looking at a family and a person with a disability, sometimes they live within the context of their family, then over time, right, institutions happen and the services isolated the individual or the student from their family and the rest of the community. But what integrated supports are is these supports not only benefit the individual or the student, but it benefits the family.

It benefits the community. And it benefits everyone. So when we're talking about the star how many points are in a star? Let's see... in the chat, how many points do we have in this star that we see? three points? five points? Five points, yes! So there are five different types of supports that we're taking a look when we're talking about planning, okay? The first step we have is personal strength and support.

Realistically the best person that can support yourself is yourself, right? You know yourself best, and to be honest, your personality traits fit you and who you are, right? We want to be outgoing. These are the things that we as ourselves bring to the table.

Next we have technology. Now over time, right, our iPhones, our smartphones, take care of everything.

You can ask your smartphone to set an alarm. You can tell Google to broadcast throughout the house, but realistically these technological supports help us live that good life. We even use, right, that doorbell system, when it comes to seeing who's outside. It's all of these different types of technology help us get through the day, and also helps us get through the marathon.

Also relationships. Just like what Tricia was saying, right? There's different relationships that someone will have, and that can support. She had her son that could help when he was leaving school to help change his brother, and it's just different people around us can help support us to get through the different changes that we have throughout life. Last, but not least, community resources. These are the places that you go to often. These are the places that you go to for support, and these are the places that where you learn, and just places that are in the community that can help bring our lives into fruition.

It can help bring our goals into fruition.

And last but not least, realistically some of us rely on them. And these are eligibility-specific.

Many times throughout life, and just throughout the transition, we tend to solely focus on what the eligibility, or what my child will be eligible for.

But what a big shift is, is that's only just a part of what a good life looks like.

And realistically, those supports still continue to help us live that good life. So with the Supporting Families Framework all people, whether you have a disability or not, have the right to live, love, work, and play and pursue their dreams in the community. And this is a big shift that DDD has been working towards--to make sure that, you know, we come back to what it's all about.

And it's all about supporting our families, and supporting the individuals we serve. And support.

So again, this framework is not specific to DDD. It's not specific to anything at all, but it's specific to life. We want to make sure that everybody can benefit from it, and that's the shift that we as a system are making. And we'd like to spread this joy or the, you know, the good news. And what good is it, if we believe in such a framework, if we don't share it. So we have information in regards to the LifeCourse framework available on our website, and for those of you folks who have a student or have a child that are receiving services from DDD, then you know that, right, we've been integrating this framework in everything we do for the last three or four years.

So I feel that the next presentation is the best that anyone could ever imagine, and I feel that hearing from families themselves will help bring this picture of how we have used the LifeCourse framework into reality. So it is with my honor that I introduce the most fantastic duo that you will ever meet are the Manfredis. We have Michelle and Renee that is here with us today to talk about the LifeCourse framework, and how the tools they have used to help them live that good life, right? It's not just about the tools. It's that framework. It's that shift. And planning for the future, planning throughout life, and

looking at our different dreams we have. So today they were going to be sharing two different perspectives. The first perspective is of a student, is of an individual, is of someone who is living this life. The second perspective that we are going to hear is we are going to hear from mom. We're going to hear from Michelle, and how she has used the LifeCourse framework to help support Renee to achieve that good life.

All right, Renee. I am turning it over to you, and when you are ready, I'll go ahead and advance the slides for you.

Aloha everyone and good morning. My name is Renee Manfredi as you heard, and today I will be sharing one of the things that I learned when I was in Kansas City, Missouri for Charting the LifeCourse was my story, my hopes, and my dreams, and how I use that for myself.

So I am 35 years old. I am a member of the Hawaii Self-Advocacy Advisory Council or SAAC.

I was the former president for the Hawaii Self-Advocacy Advisory Council.

I'm also a DD Council member for the State of Hawaii. I am a Toastmaster, a Special Olympics Hawaii athlete staff member and Sergeant Shriver International Global Messenger.

As an added bonus I have been, I have been doing these virtual runs throughout Covid.

So this is my story from 2018. I was 32 years old. My birthday is September 16, 1985. When I was younger, I thought I wanted to be a dolphin trainer.

Now that I'm older, I think I would like to be a public speaker, because I want to share my story.

This is the second part of my story. I was 32.

My hopes and dreams are, and still are, to become a public speaker, but my action plan for that was to include sharing my story with others and continuing my training as a Toastmaster, well as a Global Messenger, and as the president for the Self-Advocacy Advisory Council, because I really wanted to raise awareness and empower others.

So let's fast forward a few years later. Now I'm 35 years old. My birthday is still September 16, 1985. No change there. When I was younger,

I thought I wanted to be a dolphin trainer, but now that I am older, I think I would like to continue in my training as a public speaker.

Because I've seen that I can make a positive impact by sharing my story, and I want to continue to do so for the lives of individuals with intellectual and developmental disabilities.

My act, my hopes and dreams are to continue with my public speaking as I mentioned earlier, but on an international level. I'd like to travel, and I would love to compete in the world games for Special Olympics. My action plans include accepting speaking opportunities and attending various classes. I would also like to continue to improve my knowledge and my skills, and as for the world games, I'm hoping to continue to improve in my sports and hopefully be selected one day.

I love this, this my story, because it helped me to see things about myself that I never knew were there. Because and, I also look forward to seeing how my hopes and dreams will change later on down the road, because that's what life is. Life is about change, and it keeps moving forward, and you never know what you're gonna find. Thank you.

Good morning everyone. My name is Michelle Manfredi as Abi said, and I sure do feel like I am following some great speakers here, but I'll do my best this morning.

So a little bit about our background. We won't stay here long, but we moved here in 2005 when Renee was in her last year at the DOE. And we didn't get any sort of, you know, job training or services that led us to DVR. And at the time, the services that DVR provided Renee didn't qualify, because she didn't meet a math proficiency test for those.

And eventually we asked about DDD and Renee was denied services eventually in the end, so that left us basically having to create our own story. And so with that in mind, we looked at every opportunity that was afforded or provided to Renee as, you know, learning a new job skill.

I, my husband and I, had to, we made some choices in our life and about what our future would look like, and how to support Renee and her new role as a young adult out of school but not having certain supports that she needed. So for us, for me, what this looked like was that I would partner with her, so that she didn't have to do these things by herself.

We lived in a wonderful community that helped create jobs for her. She did pet sitting. She did a little housekeeping. She did a little babysitting. And we were very active in our church. that helped grow some skills for her. Next slide, Abi.

So throughout this time of Renee's development, some opportunities came. She was on Hawaii Stars in 2007, and she won, and I think that was her first little taste of what it was like to be in front of people. She would join Special Olympics, which she was very afraid to do by the way, because sports is not where she excels. And so we were scared of that. But we went with the attitude that we'll go, we don't like it, we don't have to go back. And that led to speaking opportunities.

It led to the Self-Advocacy Advisory Council where Renee began to gain some speaking skills.

You can go to the next one. So as Abi mentioned, this is the national data, and there's the nice little arrow of where we are. Renee is in this 75% of someone who has a diagnosis but doesn't meet the eligibility criteria, and that definitely leaves you having to think creatively. So for a parent, struggling for answers, and basically making them up as we go along, and trying to get every opportunity as an opportunity that would be a positive in Renee's life, we learned about the Community of Practice.

And this star was one of the first things that I did that really helped me see kind of where we were in our life, and where Renee was. So I want to explain how we did our star. So the first thing is Renee is the center of the star.

And then we go through each domain and filling it out. What are Renee's strengths and assets?

And for this I tried to look at everything.

Renee is friendly and engaging, she was learning to be a public speaker, she reads and writes, she's a hard worker, she's outgoing, and she sings. And for all of these things, you know, you just kind of keep

adding on what are a person's personal strengths. And sometimes there are things that maybe you're not really thinking of in that way. The next one, Abi.

Thanks. So then we went to technology, and for me, when I was going to fill out the technology star, I thought, "oh. There's nothing there."

Rene doesn't like technology, but actually there was quite a bit there. Renee doesn't love an iPad, but Renee likes to watch Netflix on an iPad, and so she figured out how to use the iPad again.

Internet. Renee isn't really somebody that's doing a lot of research on the internet, but she likes to find out about the people in her movies that she likes. And so with all of these technologies, we've been able to Web out something. The first thing I find is that we're learning, because of what our interest is. Not just for the sake of learning. And then we added the credit card, and for us the credit card has been a huge umbilical cord. And I want to just talk about that for a second, because I have a lot of people come up to me and say, "oh, my person isn't ready for a credit card yet." And I don't know that Renee was ready for a credit card.

My goal with the credit card was that Renee would have a successful experience shopping independently for an item, and to not be confused at the cash register with all the instructions being thrown at her. Renee doesn't process a lot of questions being asked at her at one time, and she tends to begin to shut down. And so I thought, well, how can I make this a success.

And so, if I give her a credit card, when it starts to be confusing for her, she can just hand the person the credit card. They'll take it, and they'll know what to do with it, and they'll give it back, if the purchase is wrong.

If the purchase is too much, we will go back at another time and solve the problem. But her immediate problem will be solved through that. So we did pretty well in the technology star area, and we'll move on to relationships. This is where our star is a little bit uneven, because I'm going to be a lot of people in Renee's life, and when I was filling the star up for the first time, the first name I wrote down was simply my own, because I'm the one that's working as her mentor, or as a PA.

You know I'm her driver, and I thought, wow! We really have an uneven star going on here, but it's our star, and it is uneven, and we'll look at that later. You begin to add more people who fill in different roles. The people in tiny print are like my husband, her sister, her brother-in-law, her brother. And while they love her and support her, they all do work full-time now, and so we have to plan a little bit further out on how their support comes into play.

Then you go to the community-based supports, and this has been something. This was another area that I really had to think about--who and what do we have in our community that's going to help us.

And it's something that you can continue to add onto, but the first time I did this, I thought, wow! We don't really have a lot going on there.

How can we create more support areas in her life?

And one of our new ones created through COVID is our Rec Center. It was something we hadn't been utilizing, but now we do. We go, they know her, and she can go alone. And so that's another community support that we could recently add, as well as the virtual walks.

Our last one that is a little bit slim for us would be eligible, eligibility specific.

Rene just qualified for SSI and recently SNAP.

And we added insurance, because that does help her be the healthy person that she'd like to be.

And Special Olympics, it was something I hadn't really considered, but there is an eligibility to be in Special Olympics. Anyone can be, you can be a Unified Partner, but for Renee, the way she is in, is because she is a person with an intellectual disability. And so I looked at our full star, and I was able to see where we were very strong, and then where we weren't so strong. And I was able to give it a little more thought. The star really pulled it out for me. And in the areas where I thought, wow! I'm really tired in this area. Or wow!

We're not really getting it, it doesn't feel like we're getting support. I was able to see, yep. That's exactly it. You should be tired.

And no, you're not getting support. And then in other areas that I hadn't even considered,

I could see, wow! There's a lot of strength going on in those areas, and how can I and she work together and pull them together to be, to continue an upward trajectory.

So one of the things that I love about this star is that you can use the star for anything. We've used it for searching goals, for going in the store, you know. I want to go in the store independently. And where each of those arms of that star can come in to support Renee in her goal. I know people who have used it in buying a car. So, you know, you put buying the car in there, and all of the areas that can support you, and you're an individual with this.

For me, this was kind of, this was one of my first real eye-opening tools was seeing exactly what was in our life and how it could play together to help Renee continue to have the life that Renee was wanting. For us, what does a good life look like is always for me, it's what makes Renee happy. And so that was, those were things we put in the star--what would make you happy.

And then we began looking on how to achieve those goals. So in closing, I really love this, and I hope that it will help you in planning for your child. Do you have any closing thoughts?

I just, you know this, these things can really help you-- especially your individual with I/DD. I know that the My Story bit was something I really enjoyed, because it can bring out something that you never knew about yourself. Your hopes and dreams are something that you want, and they change. They change throughout time. They change through every day. So you never know what you're gonna find. Thank you. Thank you.

Thank you, Abi. All right. Well thank you to

Michelle and Renee and Abi, and our amazing speakers Patricia and Patrick. Wow! I learned so much today. I hope you did, too. I have a child with a disability, and I'm thinking now, along with Renee and Michelle, how those star pieces get utilized, you know. How I start thinking about it. I teared up Michelle when you said, you know, what's a good life for Renee--it's her being happy. That's what we want for our kids, right?

For them to be happy. So that really resonated with me. Thank you so much.

If there are any questions in the chat, go ahead and place them there now, so that we can ask our speakers while they're here. Jackie, did we have any in there? Yes,

Amanda. We have a few questions. The first one for Michelle and Renee:

How are you using your integrated supports to plan for your move to Texas?

And then we have a couple for Tricia and Patrick after.

We actually are using that to plan for our move to Texas. We're looking at the supports, the activities that Renee is involved with here, because as our star showed, we don't get a lot of support. Some of those supports will just transfer, like SSI, and then we start over in a new state looking at what that state will have.

But we now have a list. We have a list starting from here. A great list of organizations like the DD Council, the Self-Advocacy Council that we are looking into, as well as Special Olympics.

And so we're taking all of that, and hopefully, being able to put it into, put it into play.

I feel a lot more prepared than I would have.

Thank you. Just please know you will be missed.

Well, we're going to miss this. Yes absolutely.

Okay, also for Tricia and Patrick:

Which marathon skills have been the most important for you over time?

All right, for you. For me personally it's the importance of having a group of either professionals and friends that can support you in what you're doing. That without that support, the emotional support that can come, and then the actual, the physical help that can come, you know. I was thinking back.

We never got out when the kids were young, because we have so many, but we had a friend whose kids I taught, and they had, they were in our church, and they had 14 kids of their own. And she was the only mom who would take care of Tom.

I know. She was a fantastic person. She was a nurse also, so I think that that helped her feel better, because Tom had seizures. So it was really hard for anybody, for us to find any kind of respite, and it's kind of a different story, but we always fought as special ed teachers. We went down to DDD and we really work with the families that we had, so that they got respite, because we knew how much it was needed. And a couple of our sons volunteered to be the respite provider. So I looked at the skills, and my initial thing was the plan, was planning, but in the resources that the actual marathon skills, that the Turnbolls and other people have provided information, I think for me, it's... I have to know myself. I have to know what my strengths are, what my needs are, and I have to really listen, then, to myself.

I tend to try to push through, when I should maybe take some time to relax and find some humor. And life would be a lot easier, not just for me, but for all the people around me, if I would, if I would do that.

So I think between the two of us, with knowing yourself, and then those resources, that almost sums it all up. Because you know, when you need that, you need to be flexible, you know when you need to find that humor. It is so important.

Thank you. I also want to ask the moms: What was the hardest part about letting go? You know, like you have these children, and you know what we always know, that we want, we.. nobody can do for our children like we can do for them. And just how do you just learn to let go and trust that the supports that you have in place will be there?

Well for... Patricia. No you go first.

Well for us, it was a little, it was, it was different. It was hard, because in some ways we dreaded it, but in other ways we prayed for it. That Tom would pass before we would, because we had, he had a lot of siblings that would, I know would take him, that would watch him, would take care of him. But I wanted them to live their own life also, and I always thought I couldn't, that was something I could not handle, was having my child pass away, but I was there when he did. And I was prepared.

My mom had passed away the year before, and that helps. So it's a kind of a hard, a hard story, but it's emotional. But I, and in that regard, but I was glad it came. I mean we should have known. We knew every day. You'd go down and go, oh he's, yay!, he's still here. And then when it happened, it was a day, it was interesting, it was a day when his DD worker called in and wasn't able to come that day. Where he was sick or something.

So it meant that I was there caring for him when he had his nether seizure, whatever.

For our other, for even our other children without disabilities, and the one with the learning disabilities, it's hard. It's the trust part. It's trusting that you've done that job.

You will be there, if they need you.

You're never going to stop being a mom, ever, ever. I don't care how old and what kind of trouble they get into, or whatever, because we, the one had got into quite a bit of trouble. And it was a kind of a gradual in a sense letting go.

Letting her stay out maybe later at night being with her friends. Letting her make choices and find, see the consequences that occurred. And then by being there to help pick up the pieces when things didn't work out the right way.

But that was, and it's still a challenge. I mean there's still times where I'll get a text message. She's in Alaska right now. I'll get a text message, and I go, do I want to look at this, because I'm not sure it's something that... And then, you know, and then I do. And then I go okay, how can I, how can we help, you know? What can we do? And a lot of times things are going well for now, but you know, you're like this the whole time anyways. Go ahead. Go ahead. I totally agree.

I was thinking though of one of the things that has helped I think both Renee and I. It's not so much as a letting go. We really utilize that cell phone. And I have a, we have a, I have a son. Her younger brother is 10 years younger, so he is your daughter's, he's 25.

And at, for especially at his age, and everything revolved around that text message and that phone. And so I was able to really employ what I was learning with him for you know.

And with Renee, this is our umbilical cord.

This is how she will go off into an unknown circumstance, especially when that scares her, and that she doesn't feel so confident about.

But you know, she knows She's got that magic, the magic box. That all she has to do is reach out and call me or you know someone. We have a whole list of phone numbers, you know. Who's

A and who's B and who's C and who's D. And then that's her, that's become like her community of support--is who's in the phone.

And with that, I think Renee felt, you know, totally confident to go try to return some item at Victoria's Secrets. Just yesterday, but we went with a cell phone. I stay in the car. I'm not far.

You know I'm upstairs at the mall. And I said okay, what... how do you feel? I'm gonna go try this. I said okay, you've got your phone.

And you know, because then one of the problems, one of the issues that Renee runs into is Renee presents. It doesn't... people don't always see that Renee has a disability. And one of Renee's handicaps is understanding language. The faster you speak, the more hurried you are, the more confused it all becomes. It becomes very jumbled, and in her mind, as she puts it. We thought about making little business cards that say "I can't think as fast as you can speak to me." You know, she's trying to process that. But the person on the other side, like the bank teller, for instance. You know, because I'll stand back. I stand back and let Renee just, you know, go for it. And then, when it gets to be too painful, I finally step in. And you know, I finally said, "you're speaking so quickly to her."

And she said, well most customers want that. So, you know, when that happens, what used to happen is Renee would just simply leave. Well, first she would cry. That was a few years ago. She would just break down and cry right there, right in front of you. Just cry. No words, you know. And then I would wonder what was taking her so long, and I would go in and find something that I was so very sorry that had occurred. So then, then she developed to walk away. Why are you here? I don't, I didn't know what they were telling me anymore, okay? Then the phone goes with us, and you know, she's able to call. I've talked to plenty of store employees. She hands her... So for us, that's been a huge, huge, how do you let go.

That's a step one for us, and I employ that and every day.

It's baby steps over here at our house.

Thank you. That was another one of the questions we got: that you two have such a strong bond, and what has made it possible for you to grow together so well? Faith.

Yeah. Our church, our family, our faith. That's always first. The cell phone has to be second.

That's you know, that's right up there. But you know, we learned that from a younger brother.

I mean Renee learned to utilize that tool. She didn't want to, and she certainly wasn't learning it for the sake of learning. She was the co-pilot a lot of times. And she had to answer the phone, you know. And she had to text him a message.

And the days of the flip phone. And so, you know, she could type the letter "k" or "l" and he figured it out. And that was really how we started, but yes, both of those two, I think. I say, I say I'm sorry a lot.

Thank you. For Patrick and Tricia: did you use the MAPS tool when your son was in school?

We used it when we went to and became aware of it. It was never used with us initially.

We were starting in California and then moved here to Hawaii in '95. But in our program at UH, that's where we learned to use person-centered future planning. And the one that we learned was MAPS, and so we still use that. And we teach it to our pre-service teachers.

So all of the special education teachers who come out of the severe autism program at UH have that knowledge of how to conduct a MAPS meeting. I've written several articles on it, and this and that. So we actually used it with Tom ourselves, and I used it with my older son, one of my older... No he actually is my fifth child. With him and all his buddies around him. So no disability, but any, but that was very eye-opening for me. But when it was used initially with us, it was the DDD used it with us when Tom was about 22-23. And I didn't know what they were doing. I mean it was so different from the construct that we had learned as far as MAPS, that I didn't realize it was a person-centered planning what they were doing at that time. Until

I got the report back, and then it had at the top of it "person-centered planning." And I was like, wait a minute! I've done all this research on that. That wasn't person-centered planning, but they did it. I mean they did get our input, but it wasn't, it wasn't really the way we, you know, we teach it, or we want it to be done. I love this life skills coaching thing. I really love that, and I'm looking at maybe, well I'm retiring. But maybe talking to other people about branching out to giving options, perhaps more from the MAPS, because one of the things that we found with MAPS is it's not necessarily culturally relevant. So that's been my focus on... it has been to how do we address cultural differences in these programs or planning processes that we have, and that are very kind of western in construct.

And so, one that we, I used to use, too, is called

Ohana Conferencing. It has a whole different... it's a little, it's very different, but I think it's actually fits better, because the parents make the decision, the final decision as far as the plan. The professionals leave the room, and it's the professional, that's the parents who come together and they make the plan for their child. So anyways, yeah. That was our experience.

You know, isn't it odd as teachers so often, we're the ones that develop the individual education plan or program, and yet the kid's with us five-six hours a day. The rest of the time, in the rest of his life, that child is with the family.

And so often, parents are left out of the loop in the development of a plan that's supposed to be, you know. What happened with me, I had a student, and he was in second grade.

In second grade, I kid you not. And then years went by, and I then began working at UH and at UH I supervise student teachers. One of the settings I went to was Keaau High School on the Big Island from, I was living on Oahu. And I went there, and I went into the classroom, and, you know who was there? The same boy that I had in second grade, but then you know what? When I looked at the IEP he was working on, one of the same goals that he had when he was second grade. And I got news for you! That child eight years later is in 10th grade, and he's still working on the same goal.

If you haven't mastered it, it ain't gonna happen.

So get rid of it. Yeah. We had meetings for our students, though, I mean, when we were specialized teachers. And actually our big thing was to find a place where the families would feel comfortable, so we had them. We used to hold them at our house.

One: it would make me clean the house, which was absolutely fantastic, because I don't clean unless I'm having company. But the other was that it was a very informal. I mean they felt great. And we had food and, you know, it was a really nice place where people felt, where they could be honest and open. But I was, we were kind of rebel teachers, and that's why we had, we left and went to UH, I guess.

You guys were just ahead of your time, that's all.

We do have a question from Chris asking: did either of the parents--you or Michelle--did you ever consider or try to put your child in a group home? Why or why not? Chris says she's an old mom, and she's concerned about where her son will live when she's gone, and wondering about group homes here on Oahu. She currently lives on Maui, and she wants to know if there's also any parents out there that have transitioned their child from home to group home. And how did that look? I know that's a bunch of questions.

If you need me to repeat anything, let me know.

So Renee doesn't. Hi Chris. Renee doesn't live in a group home. Renee lives here with us.

That's what Renee, we talk about it, and again, I let that be Renee's choice. I can certainly understand your concerns. I just had a friend pass away, and this was very much a concern of hers, you know. The forward motion for her daughter with an intellectual disability.

Which brought this to way more of a forefront in my mind than it had been. As we age, and what the plan will be, and when do, when does a person enact that plan? When is the right time?

So I might be speaking ahead. Is Debbie going to be presenting at the next one about Ian,

Susan or Amanda? Yes. We plan to have her and Ian on the next workshop in June. Can you just speak that the next one will have a great story that addresses this?

Absolutely. So stay tuned for our June 19th, because we will have three family pairs talking about their experiences. So that might be, Chris, where that gets answered a little better as well.

So when I saw her presentation about her son living in a group home,

I was very inspired by it. So I encourage you to join the next one, if you can. And it's one of those questions that Renee and I...it does not get answered today. It's on the table. So something that for younger parents... I guess I always wanted answers, you know. You want to know what, and you want to know when, and you want to know now. And what I've learned is, it's a marathon.

And right, it's a marathon. It's not a sprint, and answers, some answers, come and some unfold, and this is one of those for our family and for Renee that is an unfolding answer for her.

And it's, you know, we will answer it, I guess, in her time. Hopefully, we will have that time.

Yes. Okay. You know when Thomas about 10, we had an IEP meeting, and a doctor there at the meeting asked us if we'd ever thought about an institution. And I thought they were talking about me, because at that point in time, when we had five or six kids, I was ready for one.

But get real! Do you know if you have a child with a severe disability, I don't know if you're going to find an institution for that child, unless you either a) are fabulously wealthy or b) I don't think you'd want to be at that place personally. What would I mean that was an option for Tom? Did we really want him to go to Easter Seals with adults who would be sitting there making, cutting out Valentine hearts for the 41st year they were alive? Ahhh.

I guess Patrick, you didn't know this, but I started looking into... I can't remember the name now, but there was a like a farm--I want to say Nowen-- it was a spiritual person. But they started this idea of having farms, and then having individuals with disabilities work on the farms, and then they would live there. And I forget the French person, French name. And I think it may be in Canada or something where they had... I forget that, but I did a lot of not serious research, but just looking into what are some of the possibilities that could be available... that might be fun for him. Because our kids went off to college, and they were with their friends. And I don't even want to know what went on there at that time in their life. But I felt like there was a part of life that was missing for Tom. And it was that part of, when his brothers, they were, I mean we had eight kids in how many? Eight years or ten years or something. So they're close. So when his brothers would bring their friends home,

Tom lit up. He was happy. He loved it. And I kept thinking, this is who he needs to be with.

This is... he would love this. But I never we never really found anything that would work.

And I don't know whether I would have been able to let him go, either, even though I would have known that this is something that maybe he would have really enjoyed. It was, I don't know, a little bit hard. I don't, it didn't come up, so maybe that was part of that marathon, where I had to adjust, and just go, it's okay, you'll be with us. I can't remember the guy's name.

Okay. Well thank you so much for our team for answering our questions. If you have more, you can always email them to SPIN, and we can try and get them answered for you. But it does come down, really, to a personal decision for your family, and checking out all the resources that you have around you. Visit places, if you're looking for a day program or a home, and see how your person likes it. See how they respond to it. Do they want to be there? Do they seem standoffish? Can you make plans to visit? So all of those things that you can do, as you're working through planning for your child as an adult. So I want to thank all of our presenters today. From the DDD training unit,

Abigail. Thank you. Thank you to Pat and Tricia from the UH School of Education, and thank you to Michelle and Renee, our wonderful parent and youth duo. Really loved hearing those stories today! All right. So on behalf of Susan Rocco and our SPIN advisors, we thank you so much for joining us today. Have a wonderful Saturday, and Happy Mother's Day tomorrow. Aloha! Aloha. Aloha.

Bye. We should do the song... Aloha.