

OCALI | Podcast – From my Perspective

Belonging Series – Vision for a Good Life

JEN BAVRY: Welcome to From My Perspective. This is OCALI's Family and Community Outreach Center podcast. In these podcasts, you will hear from people with disabilities, their families, friends, co-workers, and neighbors. You'll hear about everyday life, their passions, their interests, their opinions. You'll be inspired. You might laugh or cry, but most importantly, you will better understand what life is like from our perspective.

I am your host Jen Bavry, program director of the OCALI Family and Community Outreach Center. This episode explores creating a vision for a good life supported by connections, belonging, community, and being valued. Joining me for this conversation are Celia and LaDonna. I had the pleasure of hearing them speak at an event for families and professionals, and was moved by their personal stories, as well as their efforts to support others with living their best lives. Celia and LaDonna share these personal and professional experiences during this episode, as well as offer a set of tools called Charting the Life Course that helped to build a better understanding about what a good life means for a person, and how to get started in creating that vision to support that good life.

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JEN BAVRY: Welcome Celia and LaDonna to OCALI's From My Perspective.

CELIA: Hi, thanks for having us.

LADONNA: Yes, thank you so much for having us. It's a pleasure to be here today.

JEN BAVRY: I had the opportunity to hear the two of you present a couple of months ago at a transition boot camp. And I was just so moved by your personal stories that you shared and just all of the efforts and contributions to support other people in their journey. And I just, I wanted to be able to share you two with others. So I'm just really excited to be able to have you both here. So I thought if you're OK with this, let's go ahead and start with maybe just sharing a little bit about yourself, kind of your personal journey, and how it landed you here, and what you're doing now to really help support families and people with disabilities. And LaDonna, why don't you go ahead and start.

LADONNA: So yes, so my personal journey began with the birth of my second daughter. My husband and I, we have a blended family, and we've got four adult children now. And our daughter, India, when she was born, she was born with massive brain damage, and they didn't think that she would make it past 24 hours of life. And actually, they gave me a Polaroid picture of her, and they said, keep this picture because we're not sure she's going to make it. And I don't know. It was just so devastating to me. And I was really young at the time. And I was just like, I'm going to do everything that I can that if this child lives, I'm going to give her the best life

that I could possibly have. And I think the journey really began there because I was so determined that I was going to help her have the best life, and I knew that we could do that together.

And we actually made a contract, her and I. While she was in the hospital, I went by her side, she was in the NICU, and I said to her, I said, India, if you would just fight to live, I would be your arms, your legs, your voice. I would be everything you need me to be until you can do those things for yourself. And she looked at me with an affirming yes, and she squeezed my little finger, and that was our confirmation. And we became a team, and I was her voice, her arms and legs, I did whatever she needed me to do during the course of her life.

And so I'm a, I'm a licensed, independent social worker. And I work in a local hospital, and I'm an advocate and a fierce mama bear, so that's me.

CELIA: I love that. So I come to this work, as I always tell people when I'm sharing that I come to this work not only as a mom. And that's really where I identified with the role of being a parent of a child with disability first. It was in that school place, and that's where I learned kind of about advocacy and all that kind of stuff. But I also am a sibling of an individual with a disability, and I am a sister-in-law. and I'm also an aunt. So I come from this lens of folks with differences. It's just been kind of life, but we all have to figure out life, right, and we each do it different ways. And so that's really what brought me to this space and what keeps me here are families like LaDonna's. I just tell you it's such a privilege to be in a space and share space with families, and to hold up those family stories, and to empower the family voice, it's part of my favorite part of my work.

JEN BAVRY: You two are amazing. As I mentioned, I heard you guys speak together before, and once again I'm hearing that same passion. I'd like to hear more from both of you on what does it mean to you for someone, for you, for your loved one, for others to have this best life, you know, this vision for a good life. And so maybe Celia, you can share a little bit and then LaDonna.

CELIA: Sure, so I think I have the privilege of kind of this good life vision being part of my day to day work in my role as a family support coordinator at the UCEDD and so I've had the privilege of going on this journey with families, and really looking at what does it truly mean to have a good life, and it really comes down to the people that we're connecting with, the places that we belong, our sense of community, and then my favorite spot, which is that having value.

And I always kind of use the phrase of being missed when you're gone, and we don't realize when that's missing until we feel terribly isolated. And we, I self isolate. As family members of individuals with disabilities, when things get hard our instinct is to pull away and not reach out. And so I think that part of it is really important when we talk to families of, number one, giving them permission to have a vision. I think a lot of times we give that up when we look to experts. You can get help from school. You can get help from systems to create that vision, but really that comes from what you want and what you see, and not what is safe to vision or is possible.

I have a new phrase that I use that is, moving from that lens of disability to possibility. What I love about my role is I get to look at families and go don't build it based on what's available, build it on what you want. When we do vision planning as professionals, it's not about what we have, it's about what the family wants.

JEN BAVRY: I love what you talk about there at the end, about it's what you want, it's not where you are now, but where you're going to be or where you want to be. So thank you for sharing that. LaDonna, your thoughts on how does having this vision of a good life really benefit a person.

LADONNA: Well first of all, I like to say that Celia she you did a good job girl at defining what a good life looks like. And I ditto everything that you said. You know, it really is about inclusion and valuing an individual.

See, I look at it like this, we have but one life and we should live it to the fullest. We should guide our children, our patients, students, parents to envision what a good life looks like for them, and then we should create that life. So often when I'm working with patients and parents, I go into the clinic room, and I will ask the patient, what vision do you have, or what's your goal, where do you see yourself a year from now or five years from now, and I will ask parents the same thing. And oftentimes, they haven't thought about a vision because they're living day to day, just trying to make it from day to day. And I like to encourage family members and patients to just think about what an envision, what a vision looks like for them.

So oftentimes, there is far much focus on what an individual's diagnosis or disability is, and Celia already talked about this. And the focus does need to change to what the abilities of the individual are, and or what we can bring, such as the joy, the light, the inspiration into their lives.

For example, our daughter, India, she enjoyed dancing, singing, being around others. She absolutely loved, loved shoes. And so while she was in high school, she participated in the drill team and after school dances. We made sure that all this happened. And she was one of the cheerleaders and she would cheer from her wheelchair. So after graduation, she couldn't do those things anymore, and she was at home. So we were like, oh my goodness, we've got to figure out a way to bring all of the things that she enjoyed doing while in school home to her. So we brought dancing, and music, and singing right into our home where she was. And then we captured each of those moments and memories by taking photographs, videotaping it, paintings, and then leaving all of those memories within our hearts. I made books for her about her. We would read them with her and to her. She loved it, and so did I. It's about being intentional, regarding how you will support your child, your loved one, the patient, student, et cetera, and helping them create this good life for them.

JEN BAVRY: That's beautiful. I love that you did, you brought everything back home, and that she had access to all of the fun things. And so I assume that became a family affair then.

LADONNA: Absolutely, we had, we created a village for her, and so the neighbors got involved. I mean we just really did because it was very important to us. And so we made our vision so clear that people wanted to grab on to that vision and make it a reality.

JEN BAVRY: So I'm glad that you talked about how you guys thought about and created this vision because I know you both promote, there's a tool out there called Charting the Life Course that is to be able to support people and families with that exact step, like how do you create this vision, how do you factor in all of the pieces to create this trajectory, I guess, this path for a good vision. So I think it would be great if people can hear a little bit more about that.

CELIA: So anybody can use it. So that's the one thing that we always say. And it's really evident when you have the privilege of being the room and seeing the power of playing with the tools.

So this really came out of a group of stakeholders coming together and saying, what does it truly mean to support families. It really was driven by, wasn't driven by we need a vision planning tool, it was what do families need to feel supported. And in that conversation, families and stakeholders shared their experiences of what this looked like, and out of this bubble these principles that kind of guide what we do and how we support families overall, and then in addition to that, came these tools. And it's all built on this core belief, that all people have the right to live, love, work, play, learn, and seek out their life aspirations in their own community. And they came up with tools that helped talk about that and really that's where that good life came from. It's what is it that it takes to have a good life. We're all trying to manage to get the best life we can get with what we have going on at the current time.

But as important as recognize what that good life is is what is that we don't want in our life. And we often tell families, and talk about, and families share with us that a lot of our life becomes about avoiding what we don't want. And when we're in our most difficult journeys, we're looking at that box a lot. But if we can recognize that ahead of time, what's important to us, and what we really want, and kind of know what it is that we're trying to avoid, that idea, when you use the word trajectory you know that's an upward moving line and when I'm on a trajectory and I fall off, if I know where I'm headed, and I know what I'm trying to avoid, it's easier to right myself. And it doesn't take as much time and energy because I can stay wayward on the way that I want to go.

And it's called life course for a reason, because you can jump in at any time. You know, families go, oh why didn't I know about this sooner, why didn't someone say something sooner. And we're like we're here right now, let's just talk about what you're trying to make happen, and what your child wants. It's a beautiful thing because it becomes about the family. You really recognize that family has a huge role, and that idea that the individual is always surrounded by their family. LaDonna's stories are just so obvious of how important the role was, and originally, initially systems were set up to serve the individual. I mean, we're person centered for a reason, but at the same time, you cannot ignore the impact of the family and their journey when you look at the individuals that we support and serve. And as family members, we don't want to be ignored, and we're not going to feel great about systems who are saying we want to support you but can't look at all of us and go, oh we have to take into consideration what they're all

going through. And LaDonna probably could just share more about that whole piece, but I just think that Charting the Life Course has a lot of great spaces in just embracing the principles and the framework, but also the tools are a great way to go about that, and it helps you analyze your past and know where you want to move forward.

LADONNA: And so I could just share that when we used the Charting the Life Course for India in our family, some of our concerns were making sure that she had a daily life schedule, and that we did concurrent planning, and made sure that she had the support that she needed.

And if I could just go back a little bit, in April of 2016, India was diagnosed with hypothermia dysautonomia, and that is a diagnosis that has to do with the brain's ability to regulate an individual's temperature, body temperature. There is no cure for that diagnosis. And so my husband and I and our family, we sat down and we knew we needed to change gears a little bit to think a little bit more about how to continue to create quality of life for Miss India and to make that life joyful for her and for us given the news that we had.

So we took a look at the Charting the Life Course, and we began thinking about, OK, what do we want for India. If something happened to us as her parents during this time frame, because we didn't have an expiration date but we knew we had a diagnosis that was not curable, who would provide care for her. And then if something happened to India, did we have a plan in place. So we were concerned about transition, and how to make sure that we still had social connectedness for her, and, you know, that we still had the supports that she needed.

And so what the tool helped us figure out is that we had a lot of support system. We were able to see it down on paper, and it was very clear. And then where we needed improvement or where we needed where the gaps were, so one of the huge gaps that we had was nursing. We didn't have dependable nursing. We had the hours. We had a way of getting it paid for. We just couldn't find the nurses. So we were able to take that information that we saw on paper, and then come up with a way to still make it happen. And one of those ways were, because I work at a hospital with some amazing, amazing friends and colleagues, I got together with my friends and colleagues because everyone was saying, oh LaDonna, how can we help you, what can we do to help you and your family. So I created a list and told them we really need help with India's care so that we can spend more time with her. We would have people come over, and literally just like make her formula or bring us something to eat for dinner, so I wouldn't have to worry about that, so I can get in bed and just cuddle with India, or read her book, or just focus on her, or they would come over and learn her care and sit with her for a couple of hours so my husband and I could go do something with other family members or go out to dinner. And so that's a way that you can take what you have, which is your natural supports, and see the gap that you have, and create that meaningful life that you have for your child and your family.

CELIA: I love that. That was the using of the star, which we had talked to you about the trajectory, Jen, but that's also the use of that star and knowing that the eligibility corner of the universe is where we can get a lot of our supports, but LaDonna then looked at those other four areas of the charting the life course star, that include personal strengths and assets, the relationships that you have, what's available to everybody in the community, and how to utilize

technology. And what I love is this came out of a conversation about her domain of health, if we want to get technical with the terminology, but talking about our health, but it led into community life, and it led into social and spiritual life for the family because all of that's so interconnected that when you start taking care of yourself in one space, you're really taking care of yourself in all the spaces.

LADONNA: So important, it's just, I think as caregivers, a lot of times we don't take care of ourselves because we don't think about taking care of ourselves. Our focus is on our child. And I really think it's so important that we take a step back sometimes and understand the importance of taking care of oneself because if you're not OK, your child cannot be OK. And you will eventually run out of gas, believe me, take my word, you will run out of gas, so you need to replenish yourself in any way that you can so that you can continue to help your child live out the dream that you want, and so that you can enjoy it.

JEN BAVRY: Yeah, no, I, the part about figuring out your support system and where those gaps are, I think that sometimes is the biggest challenge. It's just trying to figure out maybe if people think they don't have any but once you can sit down, you have a tool that kind of helps you look at that, it does become more clear.

LADONNA: So I am, I'm a pre-planner and the wheels in my brain are always going. It's just kind of how I focus and flow. So I think for me, I was always thinking about continually putting a smile on India's face. I'll just have to say India, in her life, she endured over 150 surgeries, and that's hard to even wrap an individual's mind around that amount of surgeries. So that is to give you an idea of the amount of pain and suffering to some degree that she had during the course of her life. So we worked really hard to give her happy days, which I do believe her good days outweighed her bad days. So I was always thinking about how to bring joy to her because I knew that that was important, and that was in keeping line with my promise to her.

So another thing is I made sure that in line with having a vision for her, I also had three goals, one, that she not be in pain, one, that not suffer, and thirdly, that we give her a quality of life. And those three goals really were guiding principles for every decision that we made regarding her care. So what the tool did for me and for my family is to help us visualize. It's a great visualization of what you have and what you need. And so it helped me to see exactly what we had. So it almost gave me like a aha moment like OK, we do have these. Oh, Celia, I can use this. Oh. She was very helpful in helping me see exactly what we did have versus OK, that's OK that we don't have this, now let's look at how we can fill in that gap.

JEN BAVRY: The tool kind of gives you almost buckets that you can look at, different things that helps you sort those out because I think from what I've learned about the tool, it does have a little bit of that opportunity for flexibility to really address things as you go along in life and not that you have to set it at age five and it's what it's going to be when this individuals 25. So maybe you guys can share a little bit more about how the tool can be used in so many different ways and at so many different points along somebody's lifespan.

CELIA: So no, it has huge flexibility. We know that we can't be flexible as parents of kids with disabilities. Life's going to catch you where you are and take you where you either want to go or don't want to go. But so yes, it has a great deal of flexibility and we learn as we go.

So our vision for a five-year-old has to have the ability to change because we're going to learn from them, what they want and what they don't want. And that's one thing I do love about this tool is as it goes across the lifespan, some of the tools are written out to give you anticipatory guidance to think about those things that you might want to be thinking about in a certain life stage. And the language itself moves from are we providing to am I from the individual's voice. So we recognize that that change is going to impact because what I want and what mom and dad want or whoever my primary caregivers are aren't always going to align. And it holds everybody's voice up in the room and we're just reminds us that this is just a really rich conversation about somebody's life, and that we always have to be person centered in that space and be fixated on their wants and desires along with them being embraced by their family and that piece of it.

So yes, and it can change them, and we have to recognize the opportunities for those changes. And we talk about that, life experiences are what kind of feeds us moving along the trajectory. The more experiences we have, the more we can identify what we want in our life. If I've never jumped out of a plane, I don't know if jumping out of a plane is something I want to do on a daily basis or never. And I have to guess until I decide maybe I'll jump out of a plane and oh now I want to do that every day. And that's an exaggeration, but this idea that with each life experience, I know more about what I want or what I don't want. And with that life experience, I can then look at more opportunities to learn more and more opportunities and I tweak my vision as I go because I've learned what I like or what I don't like and I can tweak it. So you're constantly kind of revisiting what that vision is based on what new experiences you have. And so I'm always coming from a standpoint of encouraging families to have experience and take their child in and experience whatever they can. I mean, when you think about it with LaDonna, India loved music. And so I started by just playing music next to her bed. We had music boxes when they were little, but it turned into a dance party at some point. And I have to believe that that had more to do with India's response, what they learned about India's experiences that created new opportunities of trying different things.

LADONNA: Absolutely, we had dance parties because she enjoyed them, and her eyes lit up, and her smile was huge. So we wanted that. That's the response we were trying to get. And we wanted to see that, and she enjoyed herself, so that's why we did it.

What I will say is that life is a journey. And if you can imagine a journey, you're going down a road on a trip, you know, it's not a straight road. You're going to go through some winding, you're going to go through some winding roads and up some mountains and, you know, everything's not going to be A-OK all the time, and so you have to prepare for that and that's kind of how life is when I think about it.

So I think the tool because it is person centered and family centered, it helps you to figure out exactly from if there is a change in that individual's life exactly, it gives you an opportunity to recenter yourself.

JEN BAVRY: So I'm glad that you talked about that because I wanted to learn more about how do you go about starting the tool, and who should be involved in that planning.

CELIA: So I want LaDonna to talk a little bit about how the process is because it's not perfect and it's not like you have to approach it a certain way.

But the most important thing is that the individual that you're working with is in that space and in that conversation, no matter how young. And I think as parents, it's really important to us, to me, to express that it's important to keep them part of that conversation. But when you're doing this work, because it is ongoing in that living document, I start with yourself. We always say don't do this work until you've done it on yourself. So the first step, I always recommend, is to do a trajectory of what your good life looks like and what you're trying not to trying to avoid. If you're really a planner like LaDonna, you could do the full planning trajectory for yourself. But-

And then most important is that person that you're doing this work with, never for but with. And then you can expand, depending on which kind of thing is taking priority. If school, I've had families use it to have a conversation with an IEP team as their first kind of nudge into it. I've seen families use it to have a conversation about like what LaDonna talked about, where are we headed on this health, we've got a long term health journey in front of us of whatever sort, what is it that's most important to us to make sure we keep at the forefront of every decision we make. And that's a great place for it.

I think it's best done in groups, in the sense that once you've done it, especially if you're doing it with your family, for your family, or a younger child, to then say, hey, who are some other significant people in their life that could look at this and say, oh but don't forget this, or I've noticed this, and inform the document even more and make it richer. We each see richness in other people that other people may not see.

LADONNA: And I will say for our family, India is total care and she knows just a few words, but we still communicated. So we communicated a lot in her non-verbals and her facial expressions. So we still kind of knew what she wanted because we looked at all of that. And so when I started with the Charting the Life Course, I had a physical picture of her, and then I had a picture in my mind of her, and then I took it home with me, and I was visually working with her with it to make sure that I'm keeping her in mind as we're talking about what it is and what it is she wants.

JEN BAVRY: So, how would someone get started?

LADONNA: I believe that there are different methods that you can get started. I will say I received all the tools from Celia, and they were pretty self-explanatory. She worked with me, and I was able to use them, and then help my family use them as well.

CELIA: So and yes there is lifecoursetools.com. The resources in Ohio are growing exponentially. The primary place where we kind of store everything life course is at the familyresourcenetworkofohio.org.

JEN BAVRY: I think I've heard in Ohio, there are ambassadors or there are people that are connected specifically to this tool to help support families and individuals, so can you tell us a bit more about if someone is looking for help, where would they turn.

CELIA: And so again, on that Family Resource Network Of Ohio, all the ambassadors will be listed and there are over 30 ambassadors in Ohio now. We have all kinds of folks that are willing to do it. And you can always put in a request through FRNO that you want more information or you want to speak to one of the ambassadors. The flexibility of what we're able to do varies from ambassador to ambassador.

JEN BAVRY: I just I love you keep saying flexibility because I think we all need flexibility in just our lives, and how we are able to use the tools that are out there to support us in whatever changes may come. Is there any final thoughts that you want to share with listeners about just that vision for a good life and how they can make it happen.

LADONNA: Oh, I will just say that I am a girl that sees the glass half full instead of half empty. And so sometimes when I'm talking, I make it seem like this is all easy. Well what I like to say is, dreaming is the first step, and that really is easy. So having a vision, while we all can do that, you can dream and help your child to dream, and envision what you see for the future, and I highly encourage you to do that and do that today, do it immediately. It's so important. It's about living for today because your tomorrows are never promised, and every moment is important.

Filling in the gaps however will require some willingness from caregivers to be open, inviting, optimistic, forward thinking, patient, and so much more. It is work. It's intentional work. And I sit here today to say that you can do this, each of you can do this. And if you need help, help is available to you. Seek it out. You are not alone. There are other parents, other individuals, who have walked your journey, and we are here to help you.

CELIA: I've got nothing to top that. That was beautiful, LaDonna. I think when you hear a family member share from that perspective, there is power in just taking the time to have a dream. LaDonna's right, you can reach out to any one of us through that FRNO. Look at lifecoursetools.com. Look at the videos. There's so many places now where they can, you can hear others telling you why it worked for them. So if the stories we shared here doesn't, they don't fit, there's more stories both on FRNO and lifecoursetools.com. But taking that first baby step of that possibility of what can we envision is really huge.

JEN BAVRY: Absolutely, that's exactly it, that baby step and just getting started and know that there's lots of resources out there for you to get started. I can't thank you enough for sharing your experiences and your perspective. And I know that others are really going to benefit from this interview and this conversation. So thank you again

CELIA: Thank you, and Jen don't forget to share your stories.

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JEN BAVRY: Thank you for listening to this episode of From My Perspective. If you would like to learn more about Charting the Life Course, please visit lifecoursetools.com or the Family Resource Network of Ohio at frnohio.org. And please visit OCALI at ocali.org and that's O C A L I dot O R G to learn more about our resources, including other episodes of From My Perspective as well as OCALI's Inspiring Change podcast.

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