

Building Buchanan

Episode 11: Charting the Course to Meaningful Work

Guest: Cassidi Jobe

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Mike (announcer): What's happening, everybody? Thanks for tuning in. This is the *Building Buchanan* Podcast, a platform for sharing the stories of visionaries that are helping move social change forward, here and across the nation. On this podcast, we'll explore the possibilities as we get the scoop from pioneers in inclusion, community building, and making the world a better place...

And, now, here's your host, Colette Canchola Cox.

Colette: Hi, everyone! It is Colette, and we are here for an episode of Building Buchanan and today we are chatting with the fabulous Cassidi Jobe. She is the Executive Director of the Summit Future Foundation. We're just going to talk a little bit about some different things she's done in the developmental disability community for her family and for all the other families in the area. Her nonprofit is based out of Kansas City, Missouri, but they support individuals all across northwest Missouri.

Cassidi: Well, thank you for having me, Colette.

Colette: No problem! Thank you for agreeing to chat with us a little bit and share about your family's experience and kind of all the different amazing things you've done throughout the years for everyone's kiddos. It's kind of funny because you, and I don't know if you agree with this, but it seems like sometimes parents go on these missions to meet the needs of their children and then they don't—they're not even realizing, they know that they're not the only ones in that similar situation. They know there's a need but they don't really think about the impact of how many people and families they're going to impact, how many trajectories that they are going to impact along the way.

Cassidi: Absolutely. You know in my own journey I can't tell you how many times I've thought to myself, I can't be the only parent struggling with this, I can't be the only parent that wants something like this for my children and in that same you know right, the people who were my support system when my boys were young were those parents that were kind of leading the way and they were the ones who were reaching out to me and helping me, you know, whether it was to get ABA services, the legislation for ABA services put in place in the state of Missouri, and Autism Project funding wasn't a thing when my children were younger, and so you know all of that came from other families. So, it really is at the heart of what we do as families; helping other families, you know, and along the way hopefully building more inclusive communities.

Colette: Definitely. I had a similar experience in connecting with other parents early on. My experience, you know my family experience, that we had at the time when my son first got his diagnosis, we didn't know anyone else, you know, no one in our immediate friend's circle or immediate family circle, my normal area of support, they didn't have kids with a developmental disability, they didn't have kids with what he was diagnosed with at the time which was severe autism. You know they were real dramatic about like the most severe autism we've ever seen so you know to me that was like, that was..... (laughing)

Cassidi: I'm laughing because it is that; it's the dramatics. Like, they don't know how disabled your child is.



with COLETTE CANCHOLA COX



Colette: Oh, definitely it was like an out-of-body experience you know. You've got these professionals, you know, that's what they do all day long and they're like this is the most severe case we've ever seen and you're like 'What?! The most severe?'. So, you don't know where to go from there; you don't know what to even do with that information. So, we had to start reaching out to other families who had heard the same thing before, heard similar things, that were like, 'let me help you out; here's what you do. Step one calm down, step two...' Um so, tell me - I've known who you are and you know I've kind of followed your journey a little bit from afar; not in like a "stalkery" way obviously, but you know, northwest Missouri is not that big and I see stuff. So, years ago you and your husband opened a sensory gym, correct?

Cassidi: Yeah, *We Rock the Spectrum*, we opened that in 2016 and that was because of what we were talking about earlier. You know our family had this need or this desire for a place that we could take our kids that they could play, that they could be with typical and you know atypical children and not be judged for it, and it was that you know, there's got to be other families that want something like this and there were.

Colette: Yeah, I remember I was so excited when I heard that you were opening. Maybe a year, it might have been a little longer than that, we went on vacation to Florida and you know we're Googling things to do and we went to *We Rock the Spectrum* in Florida, I don't remember which city but in Florida somewhere and we spent the afternoon there and he had the best day; just all that sensory equipment, just running and playing and it really was so cool. So, I was so excited when I saw that you were opening one nearby and I know a lot of our families here in St. Joe took advantage of that and they were driving their kids to Barry Road and playing and I know that it was it was a really cool thing to have in our area. And then as your children started to get a little bit older you started looking ahead at your vision of the future and kind of, what do they need now, and then you established a new organization.

Cassidi: Right. So, it was you know, and I can tell you even when we were starting *We Rock the Spectrum*, I knew I wanted to do something with youth. I've always had a really strong passion for youth, mostly coming from my own experience as a teenager and having really crucial adults in my life who shaped what my future looks like and kind of recognizing that youth with disabilities don't really have that; they don't have a lot of the same natural experiences that youth that don't have disabilities have, and they need that and their families need them to have that. So, it was definitely a product of what is my children's future going to look like? Are they going to have opportunities for equitable employment, are they going to have opportunities for affordable housing? You know, are there people that are going to be accepting towards them? And so yeah, I started, I co-founded Summit Future Foundation in 2018 and it has been an absolutely incredible journey since then.

Colette: So, tell me a little bit more about what you guys do for Summit Future Foundation.

Cassidi: Yeah so, we at our core, we are by families, for families. Our Board of Directors is 75 percent persons with lived experiences, that being either parent advocates or self-advocates. That's incredibly important to our mission because we feel like the people that are making the decisions about the direction that our organization is going and in our services that we provide, they need to be driven by families or people that live with a disability. So, we provide an array of skill development, community participation, employment training services. One thing that makes us unique is that we are a 100 percent community-based provider. We are really passionate that people live, work, play and recreate in their community, and that that's where those experiences should be happening so those are the supports that we provide. The other thing that we have, kind of our signature program, is called *Watch Me Thrive* and that is a youth development, a family development program that focuses on preparing current high school students for what life after school-based services looks like. So, you and I both know that the majority of, you know, supports that a child or an individual receives come from school-based systems and then once they turn 21 or depending on what kind of program they're in, they lose those services and families aren't really adequately prepared for how to navigate that and you know in the dramatic sense, you hear the term they "fall off the cliff", when families really don't, there isn't that, or there's a lack of resources for families, and so that program really focuses on educating the family and then it also pairs the high school student with a job coach and they participate in work-based learning experiences in an integrated or a community-based business; so, a host site. So, it really is just kind of this comprehensive everybody's getting this immersive experience.

Colette: Yeah, and I think one thing that makes your program really unique, especially in our area, I'm unfamiliar if

they're doing it in other parts of the state, but I know at least for our area, one thing that really makes it unique is that side-by-side learning of both the parent and the young adults learning together; how are we going to navigate this transition? I mean it is a huge transition so what's out there; you know; what's our vision for that, what resources can we use; what technology can we bring in? And I also know that program uses Charting the LifeCourse as kind of a guiding teaching model for the family. Do you guys use that for the student or young adult as well or is that more on the family education piece?

Cassidi: We do; so, we use it with the entire family system. The language is embedded in everything that we do. So, we talk about what's your trajectory; what's your vision for the future? You know it really is such a fun time to be involved in family's lives because a lot of these families haven't even had conversations with their children about what does the future look like and I know you know, most families are just trying to get through the day. You know we're constantly in crisis/ sub-crisis mode and so about the future is like, that's not happening. Especially you know 2020 and the pandemic, but we create opportunities where families are having those conversations, and then we're coming through and we're reinforcing those conversations throughout their experience and *Watch Me Thrive* and the goal of that and you know this because you and I are both trained to utilize Charting the LifeCourse with our families, but it is that problem-solving tool, and so what we also stress is that a lot of families approach transition planning as if it was a checklist and it's not. Transition planning is an iterate process and we as adults go through multiple transitions throughout our life and so when we help families to understand the framework as a problem-solving tool, then it doesn't matter what transition it is, it doesn't matter if we're talking about transitioning from high school to you know young adulthood, or if we're talking about transitioning from moving out of the family home to more of a supported living situation, or we're talking about change transitioning from one job to another. The principles are the same and if you can apply them and utilize them to establish those integrated supports that are going to trajectory towards your good life, then you know you're golden.

Colette: Yeah. I always think it's interesting you know; I don't want to share; I won't go too much into detail because I've asked multiple times if I can tell the story and they always tell me I can but I didn't ask this time so I'll be vague. But I'll never forget I worked with a family a couple years back. First the mom was coming to a Good Life Group and she was thinking about the future and you know where he's gonna live and I think he was maybe a freshman at that time; he might have been a little bit younger and she felt like she you know she wanted him to live on his own. And we started talking about chores and his life experiences and you know she was trying to work through like why haven't I had that expectation for him? I don't know I think we just, I think it's like unspoken we just weren't expecting that when he was five and we just never added it back in and we all just functioned around him like a family and you know had not ever thought of it again. So, she took it home and she talked with her husband and her husband was like, 'Oh! I thought he was going to move into you know like a residential situation when he turned 18', and she was like 'why would you think that?' And he was started naming well, he doesn't know how to do this; he doesn't know how to do that. What do you mean why did I think that?' So they had this conversation then they had it with him and he was like, 'I kind of thought you guys were gonna build me a house on your property and then I was gonna get married and then um like'....., and they were like 'well, who's gonna do these household things? And he's like 'Oh i thought you would come over and do it all', and she was like

Cassidi: You see, it's these conversations that I would love being the fly on the wall for these because it really is you know with this entire family system and then you know, you get into those reciprocal roles and they involve the siblings and the siblings are like, what do you mean you guys want me to be a caregiver? We've never had these conversations and families are like why wouldn't you just assume that you were gonna be, and you know some of them are difficult conversations to have but it really is just opening up the doors for what does the person want, what does the family want? Can we establish some kind of consensus, then let's figure out what those supports need to look like and you know it is the aha moments that we get with families with the trajectory of, you know realizing, oh my gosh, all of these supports that we're currently using are pushing to exactly what we don't want. And I had my own huge life eye-opening, holy cow experience in a Charting LifeCourse training. Have I ever told you this story?

Colette: I don't think so.

Cassidi: Do we have time, can I tell my kind of mind boggling, oh my gosh I've done all the wrong things for my child

moment? So, my kiddo went to a you know private school, private ABA school and I had spent years making sure that he had all of the best therapies and all of the best things and he had all of these services, right? But what I really wanted was for him to be included. Like, I was so passionate that he would have friends and I wanted him to have, you know, just a social life basically and a personal, you know a network. And never - I mean I'm sitting there at this table and I vividly remember it - and listing out all of these supports and it was just seeing it in black and white. Everything that I have put in place has completely trajected to him towards isolation! What in the world have I done? So, I started working. I was like okay, we're changing everything. I pulled him from this private school that I fought for years to get him into, transitioned him to the high school and it's been a process; it's been challenging to say the least, but I wouldn't change it because he has friends and he's swam on the high school swim team last year, or this last fall, and you know I remember we were walking through Target and for the first time ever somebody from someone outside of our family said "hi" to him at a grocery store because they knew him, and I was like it's working!

Colette: You know, I was going to tell you that I love that you share - we're connected on Facebook- and I love that you share those swim team pictures and I actually, you know my son can swim and he loves to swim and you know you shared something just a couple weeks back and it got me like - you know how this goes - (Cassidi laughs) so I'm like calling places and I'm like you know what? Why don't I have him in swim stuff? He likes to swim, he can swim; why don't I have him involved in the community in swim? So, I think we all have our "aha" moments, I think that's why it's so important for us to connect and to you know, kind of pull back a little bit from that day to day, in that, for a lack of a better word, that "fight", because we get tunnel vision sometimes. I know I had a similar experience when I did Charting the LifeCourse and really was mapping out everything. I wanted the same thing; I wanted him to have friends. I would say like my vision of a good life for him is for him to have friends, for him to have people that care about him, all these things and then when I would do like the schedule, the long-term schedule, it would be like you know, no, he can't come to a birthday party because we have ABA at that time, and not that I don't think that he needed those supports to get him where he is now because he did and I made the best choices at that time, but there was a time when I needed to pull back and say, is this still the best path for him? Is this still what he needs? I had a dear friend at the time that she had no problem calling me out and she was asking me about it and she was very well versed in training LifeCourse already, and she was like, "Well why don't you just take him there to play?" And I'm like well, he's getting there; he's working on the skills that he needs to greet friends. And she's like, "Really? How's he doing that?" and I was like him and his therapist in my basement (chuckles) they.... She's like "Oh; well, you know maybe he could actually try that at the bounce house place, you know, like where the friends are. Maybe he would surprise you." and I'm like you know what, I didn't really want to hear that at 9:30 before I had any coffee but you're right; he probably does deserve the opportunity to just try it out. Like we're all deciding he can't do this or he wouldn't be good at this before he even has the opportunity to go check it out and there's nothing that says that those services can't be paid for. And I think that was part of it too; in my mind I heard in-home supports and I in my brain thought like that meant literally only in my home. I didn't realize that meant like those same supports can go with him to the bounce house place, to *We Rock the Spectrum* gym, to the park and they can work on those skills right then and there. He doesn't have to get ready to be part of his community in my basement.

Cassidi: Yes; I loved what you said about just kind of that, you know, we decide that our kids can't do things before we even give them a chance to try and that is something that we really work to empower our parents with transition-aged youth to understand that there's dignity in failure and we can't surround our children in a manner that they're never going to have an opportunity to fail because we're inadvertently, you know, moving them away from what they might see is their good life. And I think it comes from a place of love, that it comes from a place of concern, but none of us go through our life without failures and when we support our children that way, we're not helping them. So, we see it the most with employment where families you know, they'll say 'well, my child's never gonna work; you know, that's just never gonna be an option'. But then what are they going to do with their day? Because work whether it's paid or unpaid it enriches all of our lives. When we don't allow them to explore meaningful work, we're completely limiting their good life, their trajectory, all of the things, because we've just decided that no, they're not going to do it.

Colette: And I think it comes back to, even if you bring it like all the way back to - like I remember I used to be a little concerned that he would be picked on or bullied which obviously I still don't want him to be picked on or bullied,

it would not be a good time. I found out about some bullying but you know like I was denying him those opportunities too, of learning how to recognize when someone is unkind to you and how to deal with that, how to cross that bridge of you know, you're not a good friend; like, you make rude comments you do whatever; and then the opportunity for him to learn I don't have to tolerate that.

Cassidi: Correct.

Colette: And I know I've went on these big rants before about him sitting alone. Like, I don't want him to think it's okay for people to ignore him and to set him off to the side and so I have to put him in those spaces and remind him and talk to him about how you are allowed to go anywhere that you want to go. People aren't allowed to tell you that because you have a disability, you can't visit this establishment or you are not welcome somewhere, so I think that was hard for me as a parent because I had to open up and be willing to acknowledge that he's going to come into some situations that might be hurtful for him and it might not be kind, but my job is to teach him how to get through it, not to make sure that never happens.

Cassidi: Yes, and that for me, I went through a developing resiliency training just for my own you know, personal purposes, and we were talking about, or they were talking about how you can use that to - um, it's those experiences that are going to develop resiliency in our children and without those experiences they're not going to develop that resiliency and if you think about it that way rather than trying to foster them from never having a bad experience, well that's not developing resiliency. As adults with disabilities, they're going to have to have those skills, they're going to have to be able to self-advocate, but if we're never putting them in situations where they have to do that, they can't flex those muscles, they can't build those skills.

Colette: Yeah, definitely and I think it's so hard to realize that those skills can come later, those skills they need those so much. Like knowing when maybe a staff person is not a good fit, they're not a good - like, they need to be fired. You know, I'm sure that doesn't happen all the time but every now and then, it's probably a staff person that's not good or maybe it's a friend that only ever invites you to go somewhere if they know that you're going to pay. You know obviously every now and then you're going to cover a friend but if it starts to lean to they only invite you because you're paying, not because they enjoy your company, not because you enjoy what you're doing, then that's not.., but I think it's those skills come in earlier and we don't even attempt. I mean I think it obviously comes from a good place and love and maybe I was the only one who was trying to do this little wrap around thing on my child. But I had to also pull back and realize he needs these skills; he needs these life experiences all the way up to give him the opportunity to be an adult and be as independent as possible because I know that I, like every parent, I will not live forever and one day he will need to do this on his own.

Cassidi: Or be able to tell other people how to help him do it. And that is you know, that is that communication piece, and it is that 'how do I want to be supported'. It's you know kind of framing it in that process that all of us as parents go through, kind of that realization of they're going to need supports in some capacity.

Colette: Right.

Cassidi: So how do I establish what those supports are going to be and help them establish those supports, what those supports are going to be, but then also at the same time help them understand why those are important and how they need to let the people that are helping them know how they want to be supported. You know my kid my 14-year-old receives minimal supports, and you were talking about firing a staff member. He came to me one night and he's like, 'Mom, I have a feeling and I don't want you to be mad'. And I said well, what's your feeling? And he said 'when this staff person is around, I'm really uncomfortable'. And I was like well then, that staff person's not coming around anymore. Like, that person is a lovely person, but if you feel uncomfortable, I want you to understand that I love that you came and told me this and you need to listen to your, you know, your gut and we'll make a change. And it was wasn't convenient and our provider wasn't happy and I knew they wouldn't be, but there was no way I was going to make him feel like he needed to be in a situation where he was uncomfortable because he needed support.

Colette: Well, that's so cool that he, you know, came to you and that, you know, just that he came to you and that he was able to recognize that like, 'I don't really, can't put my finger on it but'.....

Cassidi: And that's what it was like - I don't, I've never felt this before, I don't know exactly what it is but I'm uncomfortable. Okay; enough said.

Colette: And you know I think sometimes we just don't, I mean you do spend a lot of time with, like you know, a fair amount of time with a staff person, even if it's just two hours a week. Even if you just don't care for someone; you know, even if they aren't your cup of tea, two hours is a long time to spend with someone that's just not your cup of tea.

Cassidi: Absolutely.

Colette: So, I'm trying to think of what - do you have any advice? You know I know that you've done so many different advocacy things along the way.

Cassidi: I think a more collective focus on inclusivity and push for acceptance rather than awareness, but then also just kind of like the idea of neurodiversity and just because somebody is neurodiverse doesn't mean that they need to be isolated and segregated. And it's really exciting for me because you know I look at the families that have younger children and they're the ones that have those expectations and when they come to the table with those expectations, whether that table is our education system, our community-you know, our community infrastructures, when we as parents we expect our children to be included, everybody else around us adjusts; we set that tone and I don't think a lot of families realize the impact that they have on the people around them and that those people's perception of how to treat somebody that has a developmental difference. One of the things that we used to say at *We Rock the Spectrum*, when we were working with neurotypical children on engaging with a child that had a developmental difference was you know, instead of saying don't stare, just say hi. You don't have to whisper about somebody having a disability They're fully aware they have a disability - shocker. You know it's just those little things but we as parents set that tone. And I've seen it ebb and flow; I've seen our communities go through stages where we don't have a lot of leadership, we don't have a lot of organization, we don't have a lot of things we're pushing for, but right now there is and I hope that we can move the needle on some things especially with employment because we have you know, Parker, he's a sophomore and when he was diagnosed it was 1 in 150 children you know with an autism spectrum diagnosis so if you follow that math, we have 150 high school sophomores who are going to be entering our workforce in some capacity. So, what are we doing as a community to be ready for that neurodivergency? You know those individuals are going to live in our neighborhoods, they're going to work in our businesses. They're not going to just go away, so we have to prepare for them; that's our responsibility as citizens. I'll step off my soapbox but in my opinion it's our responsibility.

Colette: No that's a great point that you bring up, and so my son is now in third grade, so this census was the very first census he was ever even included in because he was too young prior, but it was 1 in 88 when he got his diagnosis and then now it's 1 in 54. So, if you look at Parker, 1 in 150 and then coming down the pike there are now third graders, it's 1 in 88, and then you know if you look at below that it's 1 in 54; so yeah, I mean how are we preparing everyone? Businesses; how are we all looking at diversifying our workforce and making things accessible for everyone?

Cassidi: That is the question; that is what keeps me, that's what lights my fire, what keeps me awake at night because if it's not my kid, it's your kid and if it's not your kid, it's a mom that you and I haven't even met yet.

Colette: Right.

Cassidi: You don't even know their child is on the spectrum yet. Our children have a place in our society.

Colette: Definitely. Do you have any advice for, so, if there is a business owner listening or an employer hiring manager and they think, 'man I really want to hire people with disabilities. I obviously, I love everyone, I want everyone to have a chance at employment, but I don't know where to start'. Do you have any.....

Cassidi: Call me! I mean I think it starts with that desire, it starts with that intention and then it also you know what I will say is we don't have a lot of businesses that say no, they don't want to hire someone. We have a lot of businesses who will express that they don't know how to provide supports, and we'll figure that out, you know. That's a basic tenet of customized employment, you know. Let's get into a situation, let's have a conversation, let's allow the person to learn the job just like anybody else would and then let's figure out what supports we need to build in. Do those supports need to be technology, do they need to be you know, and then you go through your integrated supports. So, we do kind of walk businesses through that process with the Charting the LifeCourse the same way that we walk families through it and helping them identify what natural supports do we have in this environment, what paid supports might need to come in a la a job coach, could we build in some technology, can we make modifications? But it just starts with desire and if you have the desire to be more inclusive anything's possible.

Colette: Well, thank you so much for sharing about your experience and sharing your thoughts and knowledge and your soapbox with us.

Cassidi: Thanks for the platform!

Colette: Oh, no problem. I think that - I'm excited to see what happens for the state. I think that so many people are working to honor that vision, that vision and that goal that the people put in place for themselves and for their family member and it's really, I feel like a different mindset of how can we make this happen. You want to do this; how can we all rally around you and make this happen? What do you need? And I love that problem-solving. I've always said like, problem solving is my toxic trait. Like if you want to vent, please disclose immediately that you're just venting because if not, I'm going to start trying to fix that problem for you. This works out really well for me because I'm always like, have you tried this, have you tried that, have you ever heard of this? But thank you so much for sharing your time with us and we will have links to Cassidi's foundation, Summit Future Foundation, that she mentioned, and we'll have a couple of other guides about employment and supported employment, and things of that nature so we will have those in the bio. So, if you've listened to this and you're curious and want to learn more you can reach out to me, you can reach out to Cassidi, and we'll also include some different links for you to read a little further about Charting the LifeCourse and about some of the things that we discussed.

Cassidi: Awesome well thank you, Colette, I appreciate it.

Colette: Thank you.

[Energetic music]

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