

Building Buchanan

Episode 5: Quarantine Life

[Energetic beat]

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.



with COLETTE CANCHOLA COX



Colette: SO, today I am here with Kelly Henry. She wrote an excellent piece called "Welcome to our Quarantine".

Kelly: Welcome to our quarantine, that's right.

Colette: Welcome to our Quarantine. It is circling around social media and other autism and developmental disability sites. She really highlighted the feelings that a lot of families were having right now and kind of started some really well-thought-out conversation; like the conversation that she started was great and I know that this was a conversation that other parents had reached out to me they were feeling the same way that she was feeling but they weren't really sure how to articulate it and when her article came out, they were like, yes Kelly, or whoever this lady is, nailed it! So, if you haven't read that yet, we'll link it below. I encourage you to check it out; even if you've already read it go ahead and read it again after you listen to this episode or read it really quick before you go any further just to kind of remind yourself or to learn what it was that Kelly is talking about.

Colette: So how are you doing with all of this? Have you had another article kind of go viral like this before or is this your first one?

Kelly: Oh no, this is my first piece. It's because partly I've only made little commentaries on Facebook. I try to keep my personal posts kind of short, kind of cute and fun, not negative. And so you know, I mean maybe on my own Facebook on a great day I might have 150 or 200 responses, so to be over 2,000 it's kind of out of the realm of my experience.

Colette: So, when you sat down to write this quarantine piece was it something that you had already kind of been thinking about and how do you illustrate that, and then kind of COVID came along and gave you - like kind of pulled it all together for you - or was it something that you kind of thought of after you noticed that people were having similar experiences?

Kelly: I think, um all this whole year has been our son's senior year of high school and so I've been having a very different experience from a lot of parents in terms of their senior year and I think Connor is having a different kind of senior year than we think of as the senior year. Maybe the event that most encapsulated starting to think about this was Connor made district band, made all-state honor band and you know we were at these events that were such a celebration, but for him they didn't feel like it. We just kind of felt like we're here to check the box, we're here marking the moment that he achieved these things, proud of how hard he works and how much he achieves, but it didn't feel like a joyful celebration; it felt like a marking of the moment and as we moved ahead through the senior year we were looking at those others coming down the pike, some of which we wouldn't be part of, you know like he did not feel like prom was gonna be a good thing for him to pursue. You know obviously he would have participated in graduation had it occurred but it did not have the same kind of resonance for us that other people were anticipating, so that was sort of the start of feeling, like a little sidelined. I mean we'd been feeling it all along with that senior year and where you realize all these things that might have happened aren't happening and that's not the life he wants to live or is able to live or both, so that was kind of the initial thing and then as it became clear that we were going to engage in a variation of a quarantine for everybody, I really

started to see a lot of people who are dear friends, you know kind of lamenting the losses like, oh we won't have a final senior concert, or the kids get to give a talk and talk about their experience in band and their relationships with the band director. And I was thinking, well thank God, because those are so hard for me to sit through, because I'm just not part of - I mean even though I love these moms, like, I'm not having that experience; um you know, I mean it just wasn't fun and sol was like, thank goodness we don't have to sit through that; that was gonna be hard and painful and a little, a little sorrow, so once I started thinking about that, you know that kind of added to it and then I guess the piece that really nailed it for me too, like I should write about this if only for my own hard drive. We were, I was talking to Connor, I mean we have three kids and our middle child is less, you know, she's very sociable and has a large circle and you know this has been hard for her that um, Connor is like "this is great I don't have to like, go to that high school and it's so big and it's so loud and I have some friends but like when we sit together sometimes the kids walk by us in the hall and they're like there's all the autistic kids", or you know there'll be commentary sometimes as if they are deaf and you know, not aware, and he was like this is so great I don't have to deal with that this is the best ending to my senior year that I kind of dreamed of. And at the same time we, you know had to have a check in with a doctor on anxiety and stuff and we realized like, he's better like not I mean 100%, but like he's way less anxious, enjoying life more and I just felt like hey, like these things you're grieving; like, this is what his life is like all the time, every day, and I just wanted to articulate it and struggled to articulate it with some modicum of grace, because there's also a lot of anger sometimes you know that you're not able to have the same experience or you're wishing there was inclusion that didn't happen, so I just had to say those things.

Colette: Well I think you did such a great job. I know that I had been talking with a circle of mine – it's actually a circle at work about how we were really hoping that some conversations would be started so that on the other side of COVID, on the other side of this, we were hoping that people would start to have a better understanding or maybe increase their empathy; and not that they aren't sympathetic, not that we need all their empathy and their sympathy because we don't really want to be pitied, but I'm not sure that people really understand some of these realities for people with disabilities; kids with autism, the being isolated, struggling to maintain connections and friendships, the extreme levels of anxiety that I know a lot of people are having right now; and also you know medical rationing. Just some different things that maybe at times the disability community is aware of but other people kind of have no idea what that felt like or that it might be happening and now it's kind of the COVID-19 has kind of brought all these things to the forefront and people are talking about it, and we're like well how can we continue these conversations? you know now people kind of have a starting point to relate that to of, remember the time when no one could leave their houses for 60 days now modify that and think about what that feels like over 20 years. But we weren't really sure how to get there and we are so grateful that you got there and you wrote it so beautifully and I know I posted it on my social media and kind of asked a few folks kind of what their favorite parts were or kind of what stuck out to them, and I know one woman put that the boy making up friends for social media, and then another mom commented and agreed that her daughter has imaginary friends that she talks about. It started when she was little, more as a company thing, or for company and they've noticed as she went into high school she now talks sometimes about these imaginary friends, but they think she's doing it to try to fit in because she doesn't have anyone to talk about and so she just kind of wants to tell a story about this person to help her image, so to speak.

Kelly: Yeah I mean that particular young man I didn't really know him well when I first met him, but I noticed him and I thought, oh he reminds me of someone I know and love in some ways and in some ways not you know some ways not at all, but I always felt like, gosh I see him on Facebook, he seems to have a lot of people in his life and then as I got to know their family better I realized like those are those are snapshots, they're not his reality and as he's matured and he's attending college now I mean that I don't see him doing those; you know he's finding a little bit more of his own ground, but it is still a lonely ground that he's traversing and it doesn't involve a lot of pictures outside of those with his family maybe a few people in a band that he's part of at the college that he's attending but it's hard. I think one of the things I thought about was when you have a child or a dependent who has a developmental disability, you're not only their caregiver or their parent but you're also kind of their social life; and I guess in those teenage years that's when for people who have a more typical developmental pattern, they're seeing that split off. You know you're definitely the parent, you're not the one they want to hang out with but I think for all three of the boys described in that piece and probably a lot of people who are in this boat with us, that is their experience; is they don't see that diverging of roles and COVID-19 has brought us all to that like we're all - everybody you live with is now your friend group; that's who you can do things with and when I hear people complain about it, I don't want to say I take joy in your disappointment or your sadness at the losses but like you know I would have loved for you to have been willing to help be that social support network to us. Like I didn't see it; it felt weird to ask for it, you know. I tried sometimes to kind of tiptoe up to and ask but when they follow it through it wasn't like you could circle back and be like, hey, I saw a game party at your house on Facebook with all the kids and like we didn't know about it. I mean that's now a conversation you can have and I think the other thing that's kind of weird about it is it's really not a big deal to not be invited to a party or even two parties or three parties, right? I mean as a grownup you're, like, you don't get invited to everything, it's not personal, it's not a big deal, but I think for these kids it's not a big deal in any singular experience, but um, it's a complex system, right? So like I imagine, I think how a tree grows and when a tree grows the program in it is kind of like "make a leaf, make a leaf, make a leaf", and over time you're not just making a leaf, you're making a branch. And so, these same things like "not invited, not invited, not invited", any one

thing is just a leaf but over time it's crushing and it's much more - it becomes social anxiety that didn't exist in the first place because of that cumulative impact of iterating the exclusion. I just felt like somehow the world was right for people to hear that message like right now, 'cause it's like oh you get it - like this is what it's like.

Colette: And I think too, you know, even going back to the tree, each of those leaves is a different life experience and those build the branch that we need to keep moving up and when we don't have those life experiences it's kind of a barrier for growth. I'm gonna refer back to your piece here for a second you wrote in there "parents now feel the disappointment that their kiddo isn't going to shine at graduation", and you talked about some of the things that were canceled and that you know, just everyone is sidelined right now. Welcome to the quarantine we've been living every day since middle school when it was no longer socially acceptable to schedule a playdate for your kid", and I know that I got a few phone calls about that line and a few parents kind of said that they were feeling the same thing. Like they've been living - they've been quietly grieving things like graduation; although they're very happy for their friends you know, their children don't have prom dates, they aren't doing senior trips, just some of these things that other people celebrate and it's kind of a rite of passage, as where they have been dreading them for years because they - know that's not going to be there - they feel that that's not going to be their experience and they're really kind of nervous about what their child's life might look like and what their lives might look like after high school, because they just don't know. They talk about being the social network for their child, but then they start thinking about aging and you know how does all this fit together and so there's kind of this grief cycle that they said that they are in and it's kind of strangely comforting that other people are kind of grieving.

Kelly: I struggled with the language on that, you know, 'cause I understand it sounds like it could be read to sound like, ha! I'm glad you had a tiny taste of the grief we've been suffering'. That is not the tone I wanted to come through, but I had one friend who reviewed it for me and suggested I change the word "grief", but I was just so reluctant to do that because that is what it is. It's like a little grief every day; um, of things um, lost or not done the way everyone else is doing so I do think it's a grief cycle and at the same time you struggle with that as a parent because you, like, we want to accept our children. I mean when Connor was, oh I don't know, very small I remember thinking, like I was reading books where you know people were like, "I cured my kid with a gluten-free diet and now they're not autistic anymore" like those kinds of books, um and I guess that didn't sit well with me 'cause I kind of felt like well, you're who you are; like, I don't want to fix you; I want you to be the best you can be; um and I feel like that's not quite happened yet in high school and you know maybe no one's their best self in high school um, I feel like a lot of people get to see a little bit more of the best self of their kid in high school than people who are kind of sidelined the whole way through, so that's... that *is* grief and I don't want to call it something else.

Colette: Well, I agree and I think that there's kind of this shaming aspect from what I gathered from some of the people that reached out. There is kind of a shaming aspect to acknowledging that the grief is there and the grief exists; because it doesn't mean that they value their children any less, it doesn't mean they want to fix them or make them different but it also - they want to be able to acknowledge or talk about it without feeling judged. That when they see the 17-year-old that their kid grew up with pulling out of the driveway every morning to drive to school, that stings and sometimes it stings a *lot*

Kelly: And it stings a little bit every day. Right

Colette: And so, some of them felt very comforted to see that someone else related it to grief because not only were they feeling that way, but then they were also feeling very guilty about it, so there was a lot of emotion tied up to that because.....

Kelly: You don't want to begrudge someone's good fortune of course, and you feel like maybe you are doing that and I am with the person who reached out to you; I don't want to begrudge them but it does sting and it stings a little every day, even you know, one friend you know says how's so and so coping and they're like oh, it's fine, you know they prefer to be in school but they're very connected and just even though I don't want to begrudge that mom and her child being connected, it stung because I thought well why are they, I mean why are they not connecting with mine? Like, like, and I don't want to have to ask for it; like I wish she would have seen that and done the nudge; and we just don't live in that culture but I hope that would change.

Colette: Yeah, and another interesting thing that I've noticed with the quarantine and I don't know if you and your husband have noticed this or you and your family; a lot of things have moved to zoom; social things even for adults would have made it easier. So no, my son's still not getting invitations but they're really at an age where they really can't do that on their own, but we are able to participate in more things now socially than we were before because everyone moved to zoom. And you know it just, Friday night to meet you for happy hour just wasn't in the cards for us before. You know child care, we had to plan out very meticulously so we were, we just that would not have been something we would

have done but now that things have moved to these online platforms, which what we find strange is we are more connected to some of our social circles than we were prior to quarantine because they adjusted - the mass adjusted.

Kelly: Yeah (chuckle), yeah, quarantine - the great equalizer, and in some ways not, of course. Economically we see all kinds of big gaps, but for sure in terms of socialization and social contact it's been an equalizer. We were relatively introverted people anyway who didn't you know, spend a lot of time at happy hours but I can absolutely see where yeah, like everyone has zoom at their disposal and not a whole lot else, and you can do that because you're not having to leave the house. And I guess it's that equalizing force that I'm hoping will give this little chance for empathy; I mean I think the empathy is there but like what I haven't yet - I don't really know for sure how, but I'd like to see empathy go into action, you know, and I think the world is at best when people individually make great decisions for themselves and the people in their little sphere. And so, I don't know that I wish there was a program to, I wish that moment of empathy where you realize like, oh this is so hard, it's so isolating. What if we did happy hour out on your front lawn so you could be part of it from now on because that was so hard and it was so great for you to be part of zoom or you know like what if, I mean even though normally when the kids are 14,15,16,,17 like, we don't bring the kids along, we're like hey this time it's gonna be a family; the grown-ups are gonna have drinks here, but I'd really like for you to hang out with the kids and including so-and-so, like, because that's how, um, I mean you can say all day long, it's okay bring your kids but like to go to someone else's house who doesn't have the things that you need it's challenging, yet to always have to be hosting as hard and exhausting as well. I mean just to, like, make people aware that I come to these things when I can; I want to be part of things. The people are ready to empathize because they're having an experience that gives them that insight, so I just wanted to write this at this moment when people might be ready to take empathy into action.

Colette: I think it was great timing, I really do, and I think it's I think it's always been hard for the disabilities community to illustrate what isolation looks and feels like when you're trying to explain it to people that have no experience to kind of measure it by. They've never been in that situation before and so even just some of the transportation issues, some of the getting supplies; so just some of the things that adults with developmental disabilities you know: I can't get to the store I need food, I'm stressed about this, I need to get my medicine. Just all these things they need to do I think that this is kind of giving a marker for everyone to understand how stressful some of these things can be when you can't leave your home.

Kelly: And you know honestly, what I think we're asking for or hoping for from people around us who are entering this new awareness, is it really doesn't take much; I mean the things that we could all do for the people in our community who go through this isolation are so small; like a phone call once a month or every couple weeks, a text, you know like do you need me to go get, hey what if we went out to lunch at this place that I know you're comfortable with what if me and my son and his friend you know went to the movies? You know movies don't require a lot of conversation you know it depends on the kid you know. But I think we all know the folks in our circle who have been sidelined, we just haven't noticed them because we've been living our best life and now we're not living our best life, it's a chance to look at the other people who weren't part of that but they're in our sphere, and just do those little things that would make such a difference to those folks.

Colette: And I think I that also sometimes they might know they've been sidelined, but they don't even know how to start the conversation; they don't know what they can do and the best thing is just ask I would assume if you've got a friend ask - do you need anything or calling I mean to check in on them or check in on their kid or an invitation, like you said, here and there would probably be great

Kelly: You know I do think people don't know what to do, and you know, that's part of the problem of, you know, by the time you're in high school these patterns are sort of set or certainly early in high school they get real settled; people have a friend group and it's hard to shake that up you know. Things tend to - systems tend to settle into a zone that they just sit in and unless there's a chaotic event that disrupts them, and so we have here a chaotic event that is disrupting all the group structures that we've built in our community and like we can rethink this structure to be more inclusive now because now it's time, like the structures being rebuilt and as we do that it's a great time you know, especially if you've got like a middle school kid that you know, when they were little there was a kiddo in their class that they could play with and they felt friendly with, but you haven't seen them for a couple years right because the sidelining is starting in middle school, um, late elementary maybe even, so like that's a great moment for a parent to sit down and have a conversation with their kid in late elementary early middle school and be like, hey I know this isn't a person that you feel like you get a lot of affection from or reward from interacting with but I bet they'd love, I bet they have some things to offer. I bet if you found them in their best space you know, and what do you think that best space is you know; what was it about elementary school that made it work? Well it tended to work because you had playdates with one or two and then as they go into middle school it tends to be more larger groups and that's harder to navigate and so what if like you can still do things with your group, but what if every so often we just still did something with this kid; um, you know like just building that structure into our routine would make a big difference for not being isolated and then once you're doing it you have those points of contact where you become more aware of like, oh are you having trouble getting out to get medicine; can I

pick that up for you at the pharmacy; or oh I've got an extra thing of PediaSure for your kid on a feeding tube, let me bring it over; you know I mean it wouldn't be hard because you would know you'd be having those conversations. Whereas when your kid is 17 or 18 it does feel really awkward to be like, you know I'm sorry I've been invisible in your life for the last eight years but is there anything you need now. But I still think it'd be better to ask.

Colette: Yeah I definitely love that you started this conversation and I love that you said turning empathy into action and figuring out how we can make that work within your own circle; that no one's asking someone to build a whole program and need a lot of money or most of the barriers that comes along with a systems change but you know we don't necessarily need a system change, we need a culture change within our own communities in our own social circles to kind of realign what our values are and how we are including everyone?]. And I know what we're teaching our kids too;

Kelly: Yeah, it's a little more than the be kind message; I see that, appreciate it, I like it, but that sort of goes to the 'we were hoping for more than not a jerk'; like when you're kind you're not out there doing, but it's not necessarily active. It's not looking for the lonely, so I'd love to find a way to go beyond be kind. I'm glad there's kindness; I just wish it was a little more active.

Colette: I love that I agree I'm excited I hope that your idea of action turning the empathy into action takes hold., I know that you inspired a lot of parents with your piece and I also noticed that it resonated really heavily with some who usually don't have the same viewpoints, so that was interesting for me to see to that you really spoke to people who have very different experiences, very different views on a lot of things, but this was impactful for all of them so you really captured, I think, some great perspectives of what people with autism go through during social situations and how difficult that can be for them to experience, and then also how difficult it can be for their parents and family members to watch them experience.

Kelly: It is hard, but I appreciated the response people gave me. You know, it's a little scary when you put your heart out there that and especially a heart like that when you know some of the writing is coming from a place of pain and even a little bit of anger to try to say it in a way - I mean no one wants to be yelled at, so if you start yelling at people and telling them what they are doing wrong they are not inclined to listen, so to try to say it in a way that people would hear was what I wanted to do.

Colette: I think you did a great job of that and I'm so appreciative that you were willing to come on and share a little bit more of your heart with us and a little bit more of your thought processes.

Kelly: Well, I really appreciate the chance to chat with you and explore it a little further

Colette: Oh, well 'm so appreciative of you for writing it and spending your time on here and we will have this posted fairly quickly because we want to make sure we put this out while people are still quarantined. So we want to kind of give them a chance, especially for maybe those people that haven't seen it yet they might not be in the, you know this might really speak to their experience that they haven't seen this yet, so we want to make sure we expose them to it as well so that maybe they can feel more understood or just, I think, more understood was the message I got from a lot of a lot of families is they felt understood by you and they also felt that their children were understood. Well that's all we have time for, but be sure to tune in for part two where Kelly will be back to share her perspective and offer up some tips for making sure everyone feels welcome all the time.

[Energetic music]

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