

Building Buchanan

Episode 12: A Millennial Caregiving Tale, Part II

Guest: Rachel Hiles

[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.

Colette: Hi everyone; it's me, Colette, and I'm here with Rachel from www.takingcareofgrandma.com. for Part Two of our latest episode, we'll talk about privacy and boundaries, recruiting caregivers for her grandma, her blog and a lot more. So, you kind of mentioned something when you were chatting there that I hadn't, I mean I've thought about it, I knew about it, but I don't think I've addressed it on this podcast any or shared it with listeners. So, you kind of talked about staff and how there's kind of a little bit of a trade-off there between getting help and support you need in the home so that maybe you can do something like this, but also how it trades off privacy too. So, more help equals less privacy for both the person that needs support and the family member, so I just thought that was interesting that you brought that up.

Rachel: Yes. It has been a huge adjustment, having somebody else in my house; you know it's just very strange, I mean at least for me. Maybe for other people who have more family and are used to being around people, but it's been very different having somebody around all the time that's not really necessarily related to you and they know everything, you know, that's happening - almost, yeah, you're right that's been one very challenging aspect of all of this.

Colette: You know we didn't realize; we had gone years with staff in our home, probably not in the same way, but we would have staff come in for a couple of hours a couple of days a week, and we were always here and we always needed to be involved. But we did that for years and years and then we took a break inadvertently; we were getting married, one of our staff people, our lead staff person was having a baby, and so there was just kind of this natural break. And we realized during that natural break we might want to break a little longer because we had realized that we had never, as a family, been that amount of time without people. You know I mean? (chuckles) It sounds silly but you know without having people in your house and having..... You know most people get off from work and they go home and it's done. But it's like you have appointments, you have things, you have people coming into your home on a Monday, Wednesday or Friday, whatever it is until 7 or 8 o'clock at night so you're like, preparing dinner around these people. Which, staff is great. A lot of those people are like family to us, but don't really realize it when you're in it that it is a little, I don't know draining; I don't want to say draining; I don't want to say it like it's negative because it's not, but it is a little bit of a different feeling or experience, kind of really showing people and having people really in your home.

Rachel: It can feel at times like, you know, you really just cannot truly be yourself and let go and unwind; you know it just really depends on the connection you have with those caregivers or support staff. But yeah, it really takes some getting used to especially if you have to be around them a lot. Some people never interface with their caregivers they



with COLETTE CANCHOLA COX



are only there you know for a little while, but it's been a very interesting experience learning to deal with people and manage people and handle personalities and different backgrounds and it's just something else. And even just finding people; that's been another situation in itself.

Colette: I love your ads or posts, your marketing; like, I love the way that you advertise the jobs for your grandma. You know, "Barbara's sidekick"; and then I love that you tell about her and things she would like to do in the community and I had never seen anyone else advertise support worker jobs that way. I know you were self-directed and I know I copied it - I did - I want that. That's how I'm gonna start, but when I did, I had a lot more response than I did the other way.

Rachel: Yeah, with the standard, boring old job description. You know a lot of times in our field, caregivers or support staff are considered like glorified butt wipers or something like that, but it's really more than that. It doesn't matter if you're supporting a 32-year-old man who has autism or an 84-year-old woman with Alzheimer's, you know the fact of the matter is, generally you know when somebody hires somebody to help or care for somebody, they're looking for more than those activities of daily life and it often grows into more than that and it becomes a relationship and it's truly special when it happens. Well, so the sidekick idea I have to admit is not entirely original. A friend of mine and I were kind of working on an idea but I stole it because if you think about a superhero and you think about their sidekick, you know the superhero, they get the spotlight, but we all know that Robin is ten steps ahead of Batman you know and he doesn't steal the spotlight and that's exactly what I wanted for my grandma, is somebody who would see it more as a partnership as opposed to a power thing where they're in charge of her or they thought that they were grandma sitting. Because I gotta tell you that's one of the worst things; you feel like you're not even getting what you're paying for when somebody just kind of wants to come in and sit around and they aren't looking forward to what they're going to do, so we've tried to make it a more active role and focus less on the activities of daily living as much as we can and more on quality-of-life activities, things that bring her beauty and joy and help her feel loved and have a vast array of experiences as opposed to just sitting and staring at a wall all day or the boob tube - that's one of my major enemies in this house today. But yeah, I thought that, being very strategic about the language I used and how I describe what the sidekicks do would have a great impact on work performance and it really has. So, the other thing is I've exclusively used our personal network to recruit sidekicks for my grandmother. Only like one person out of probably ten over the past four years has been somebody I just didn't even know at all or have a connection to. So, the first sidekick was a friend of mine and then I added another friend of mine and then when I tapped out my friends, I reached out to her church. Now you can visit my blog for some tips on you know how to handle that a little better than I did, but I reached out and some very kind, concerned individual from church had some ideas and they knew some folks and so I was able to leverage some caregivers that way, but I use social media and one of the sidekicks came from a friend of mine who saw that and she was like, 'oh you know what, I think my sister would be great for that, and it was and it worked out great for a while and then of course things change and so you're constantly adapting and adjusting and toggling and trying to make it work because things may not work forever.

Colette: Yeah, I definitely, I've loved how you've strategically used language and it's taught me and I've passed it along to parents when they call me when they say that they're trying to find staff, I've passed your tips along to them to try to use their own social networks and kind of how to reframe those conversations. And I love what you just said about it being a partnership and that it's not just babysitting or it's not you're the boss of someone, you're not retraining someone. You're just supporting someone, you're just their sidekick. You're getting in there when they need you and then you are kind of fading back into the background when they don't. I love that analogy; I hadn't heard that before thanks for sharing that. So, you mentioned that people can get some more tips on your blog. What is your blog so they can check it out?

Rachel: My blog, my website is www.takingcareofgrandma.com. I launched it about four years ago now. I haven't really been active on there lately, I hate to admit, because unfortunately, my mom passed away right at the end of 2019 and it was very sudden and very unexpected and I haven't really been feeling like blogging kind of since that happened. I did not ever, you know obviously we all know nobody will ever live forever, but you just never expect that

you're going to lose one of the most important people in your life. And grief is a funny thing, you know. You think you're over it and something happens and there you go; you're in the waves again. You feel like you know, sometimes you feel like you're drowning even, but I think about my mom and then of course I think about Calvin and then I, gosh I think about grandma and you know she's not even gone yet, but of course you know caregivers also have anticipatory grief. Not only are they *going* to lose their loved one, every day they are losing their loved one and it's not easy. So, you know over the past year or so I'm just kind of taking a step back from that because I feel that obviously I've had to focus a little bit more on grandma herself. I think I was a little bit coasting; all that hard work you know getting support for her and a routine and everything she needed really paid off for a long time and we were just coasting and then all of a sudden you know, like I said, things change. But back to my blog, taking care of grandma.com, yes, I needed a way to communicate with the world all the things I was learning and feeling and experiencing and hopefully give, I mean I don't want to say advice because everybody has to figure out what's best for them, but there is some really cool stuff on there. You know I've had a lot of great opportunities open up to me thanks to www.takingcareofgrandma.com. I was able to write and record a rap video that's on there or on YouTube if you're on YouTube just type in "taking care of grandma rap". That was so fun and I don't know, I just guess I wanted to be an example and a resource to other people who are young, especially you know people like me. I'm caring for a grandparent and I'm you know a millennial (eye roll), but you know there's actually one in four caregivers nowadays are millennials and pretty soon it's gonna be a bigger number than that and it affects everybody. A lot of people think it's only women, but I know plenty of men that have to take care of their loved ones too and I just pray every day that somebody who is searching for something will find something that helps them or inspires them or points them in the right direction. So, www.takingcareofgrandma.com, yeah.

Colette: Definitely. I advise everyone who is listening to check that out. I think it has information that maybe is not valuable to you right now; you might be able to use in the future or you might be able to share it with someone when they suddenly go through a situation and they are suddenly becoming a caregiver. You know, maybe it would help you to be a support to your friend or your co-worker or your sibling or whoever it is, that may be suddenly taking on a caretaking role for someone that they love and I think that's one of the hard things too, you know sometimes friends and family members and other people have never been in that caregiving situation, so they're not sure how to be a support to the caregiver.

Rachel: That's very true; on the other side of the token there are so many people out here who have done it and are doing it and they have no idea that that's what they're doing. They didn't even realize there was a name for it. So, if that's you, there is help out there you know you can be that resource or support for somebody who might just be stepping into your role because once again it all goes back to opening your eyes. There are so many people out there and they have a similar experience and it isn't until you begin doing it that you realize, oh, I see that lady in the grocery store and you know she's toting her mom around, or oh, I heard about this fella at church and he had to you know, unfortunately, put his wife in a facility. You know it's *everywhere* as soon as you turn off your blinders, and it's coming for you.

Colette: Yeah, and I do want to, for anyone that's listening that might be a caregiver who felt that a long-term care facility was a better fit, I just want to kind of hop in here because I know that I don't, and I know that Rachel doesn't either, so if the best thing for your family member was a long-term care facility, we are not being "judgey".

Rachel: Yes! More power to you. Absolutely,

Colette: If that's the path that is best,

Rachel: Different strokes for different folks, you know. A lot of people have wondered why I haven't done something like that and it's just because I just know that I wouldn't be able to live with myself that way. I'd rather keep an eye on my grandma here. But facility placement is not a bad thing if it comes to your loved one's safety and well-being, but a lot of people think that that's the end you know. Like you put them there and that's it but you have to still, you know you have a responsibility as a loved one to carry out that commitment of love and loyalty and continue to be part of

their lives so they can still have that quality that you want them to have. Because without due diligence you know, unfortunately, some of those places can be a little scary, but you're right; there's absolutely nothing wrong with having to go to assisted living or a nursing home or anything like that.

Colette: Thank you. Can you give everyone a real quick list of some neat home mods or technology they can use in their house they can kind of get anywhere to make it cool for a caregiver and for the person? I remember a couple years back I saw on your phone; you were showing me some of your stuff and I thought that it was pretty slick.

Rachel: Yes. So, I gotta tell you for three years, Nest, Google Nest cameras were like almost probably half of the reason why my grandma was able to live independently as long as she could so thank you to Google and Nest for that. So, I highly recommend cameras; they don't have to be Nest although you know like obviously, I've kept saying that over and over again. I do really appreciate the ability to be able to check in on my grandma whenever I need to and you know there is a privacy conversation that needs to happen, but quite frankly, you forget they're there but you're so happy when you need them. You can roll back that beautiful bean footage and see , you know, maybe if somebody had a fall or something happened, you're not so sure about. My grandma used a bed rail that really helped her get in and out of bed and a lot of people swear by it. Also, a lift recliner which a lot of people have but they don't even realize you know that it's necessarily an accommodation or something like that, but a lot of people fall when they're trying to get up and sit down and so that was one way we eliminated fall risks with the lift recliner as well. And then she had medical alert for quite some time until she got to the point where she didn't know when it was appropriate to press the button or not. The EMS showed up at three in the morning, my dog wakes me up - oh, lordy. But you know I guess what I would say is there's no one-size-fits-all solution, and normally you have to find a number of solutions that will work in your particular situation. But there are some great resources out there to help you. You can contact your state assistive technology project. Here in Missouri, it's the Missouri Assistive Technology and they're incredibly helpful when it comes to figuring out the technology you need and financing for it and training. Also, AARP has a great guide it's called the *Home Fit Guide* and I'll send Colette the link for the notes, but it really focuses on looking at your house now and adjusting for future needs and so that's kind of my thing. You know it's hard to give blanket recommendations because everybody's experience is so unique, every house is different, every person is different, every caregiver is different. So, the one blanket solution is to put your thinking cap on and be creative and flexible at all times; that will really help.

Colette: That's great advice. I've been so impressed by some of the technology that I've seen; you know, you can turn TVs on and off remotely, you can turn the lights on and off. I know of a person or family who, I think theirs is Alexa but they have this system that's set up so the light bulb comes on, the lamp comes on red 30 minutes before bed and that signifies that it's time to go take some evening meds (Rachel: that's cool.) so I am in awe of some of these just everyday technologies that people are buying from Sam's Club or wherever that are helping people to live independently, when I feel like maybe 10 to 15 years ago it would have been like, that person can't stay at home because they're going to forget to take their meds. So, this light system is set to a pill thing that dispenses each pill, like exactly what pills they are supposed to take, so they can't take any extra and then if they don't open the container to get them out it texts the family and lets them know to call or check in, remind, look on the camera, see what's going on and so, I just love - like it's just so interesting to me.

Rachel: So, it is; it's awesome. We have something similar like that right now; it's not going to work much longer but a friend of mine actually presented at a conference about a setup that he had and he actually gave me a bunch of great tips and advice. But we have a Samsung Smart Things hub that's connected to the internet and lots of devices connect to it. So, we have a little white button that sits on a tray and at night if she needs help, because I'm a heavy sleeper, and originally when we were back at the old place, I couldn't hear her at night. We have a light that's plugged into a smart plug and when she presses that button it turns on in my room so it'll wake me up when she needs help. But like I said you know some solutions don't work forever, and she's not really able to figure out what the heck that button is for anymore, and so I have to now, you know, periodically wake up in the night to check on her, but it's incredible; yeah, what will they think of next? Geez Louise!

Colette: I know and I love, I just love that it's available wherever. I know that I've talked to people who have been around for you know, they're pretty seasoned, and they said that these types of technology supports were considered remote monitoring which used to be tens of thousands of dollars and like a couple pieces at a time for a couple hundred dollars each time, which couple hundred dollars is still a couple hundred dollars, but that's obtainable for people who maybe don't want to be in the formal service system. Maybe they're on a wait list so it at least gives some more affordable options to try. It's really hard for some people too, to request something for ten thousand dollars, wait six, seven months and then it doesn't work. How depressing! I don't know if you can or not but I feel like this may be frowned upon, this may be a gray area I don't know, but I feel like if you've got the Nest from Sam's Club and you tried it out for like a week and you knew like, this isn't working; this isn't doing what I wanted to do, couldn't you take it back?

Rachel: That would be so nice, wouldn't it? That's why I really recommend getting in touch with your state assistive technology project because they do have programs and things that allow you to try things before you "buy" them, or you know talk to your friends and see what they're doing. Chances are you know somebody who is already doing that and you can learn from them as well. You know I never wanted to get my grandma a medical alert but, Mary Lee, who is somebody who is very esteemed and respected in our field, was also having a similar experience with her father and she got him a medical alert and I was like well, if Mary Lee can do it then so can I. And so, it's amazing what technology can do.

Colette: You know while we've been talking, we've both mentioned different people that we've crossed paths with and are friends with along our journeys and it just made me think of the importance of connecting with other people. I've taken, I've used your experience to guide my thinking and my life in several ways. I was also thinking about Lisa; I've pulled a couple things from Lisa's experience and I'm sure there are many, many others so I just encourage anyone who might be caregiving, taking care of, whether it's a child or another family member or friend, neighbor, to reach out because we're all taking little pieces and little tricks and tips that we've found work and it can really be helpful. It can really be helpful than to just keep trying at it alone.

Rachel: Yes, you're right. my friend Amy Goyer likes to say 'I can do anything but I can't do everything' and so that's why those connections you're talking about are so incredibly important because it's just unfair to ask or expect one person to carry all of the load.

Colette: So, I want to kind of shift gears a little bit. If you could wave a magic wand and change something in the world, the whole big world, to provide more access or to make things better for people that have developmental disabilities or aging, what would it be? I know it's like a super loaded question.

Rachel: Yes, that is really a good question.

Colette: I know I put you on the spot with it.

Rachel: Yeah, that was the one thing I saw on there that I just did not have an answer for. I guess if I had a magic wand - I'm probably gonna hop up on my soapbox right now - it wouldn't be anything that I could make happen or create. If I could wave a magic wand and change something for people with disabilities and people who are getting older and need support and of course, all of their caregivers, it would probably be that expectations around caring for our fellow humans really needs to change because I think a lot of people just expect that our loved ones are gonna live forever and they're gonna be fine, they're never gonna need our help; we just don't ever think about it until, like I said earlier, it's too late. But the other thing is there's a lot of misconceptions out there about who's really supposed to take care of our loved ones when they need it. A lot of people think that the government is supposed to do it but when it comes down to it, like I was looking this morning, I was trying to make a little "All" triangle for the older adult population and Medicaid supports, and it's really looking like only ten percent of seniors over the age of 65 in the United States receive Medicaid-funded long-term supports. And Medicaid is not a bad thing, but when you have to become reliant on Medicaid it normally means that a lot of other things have to happen first and a lot of things have to

be lost first, like assets and abilities and social connections, so I guess you know I would just, rather than wave my magic wand, I would rather shake everybody, wake them up and say hey, you need to get ready because caregiving is a universal experience, do not live under a rock. Have those difficult conversations however you can, you know if you know of a friend, bring them up, like approach the subject. And it's not gonna happen all at once these are conversations that take time; they don't happen in a day but they have to happen so that everybody's clear on what's expected of them and everybody's roles are kind of mapped out because it just makes everything a lot smoother when it comes time for your loved one to receive the support that they truly need.

Colette: I love that. Thanks for sharing that little gem with us. I love that you mentioned that's a universal experience; you said that much better than I did earlier, but I also love that you also brought up "The All" triangle and the misconceptions about paid support or government support, because you also know that in the DD field only one in four people qualify for state support, so I do think you're right that there's a misconception with the community at large that if you have a disability or if you're aging you automatically have access to Medicaid or Medicare and these dollars that are going to help your family, and I think that can cause a huge shock to, whether it's parents whose child gets diagnosed with a developmental disability or is born with a developmental disability, or you know a senior; you know families take care of a senior, I think that can be very jarring um to family members and I mean this might sound a little bit dramatic but almost traumatic when they find out the cost of these services, and then also that they don't qualify or that you can't have any assets. So, they're like, what do you mean we can't have any assets, what do you mean we have to make less than twenty thousand dollars a year? So, if I do if I make more than twenty thousand dollars a year then all of a sudden I can afford three hundred dollars an hour? So, I think that causes like crisis stress but then also some trauma of trying to figure out how are they going to pay for this, how am I gonna make this work?

Rachel: Unfortunately, in other places that expectation might be true but here in the United States it's just not happening, so yes, plan early, plan ahead, accept the fact that you may make a plan and then it's probably going to change. Things change quickly. Nobody knows it better than us.

Colette: So, you've listened to this episode, we ask you to do a couple of things. We want you to share this episode around with your networks of anyone that you think that it might help. We want you to go check out www.takingcareofgrandma.com and just look through the resources that are on there, because you never know when you might need it. I really want you to see, and I might try to link that if it's on the caregiving.com, the way that Rachel advertises for help around the house, for Barbara's sidekick, because I think that the way that she presents that, it's great for so many reasons. It helps find the right people; it helps make sure there's a lot of dignity intact for her grandma. You know, she's not sharing online anything negative about Barbara, but these are the ways that you can support her. I specifically remember that she likes bingo because of those. I think it helped us, I think it helps everyone to learn more about your grandma and continue to see her for the vibrant, caring, moving and shaking, out and about woman that she was. Ask me to describe your grandma I would say she loves to cook, she loves to teach people, she loves her church, she likes bingo. I mean as long as I've known your grandma you've been her caretaker, but the things that I do know about your grandma or when she comes to my mind, that's the picture of your grandma that I get.

Rachel: Well, that's wonderful because you haven't even met my grandma and that you've retained that information so that really you know at the end of the day that's all I could ever really hope for is that people, you know, despite the dementia, continue to see my grandma for you know who she truly is so that really means a lot, thank you.

Colette: I've got one last thing before we sign off. You talked earlier about how your grandma and your mom really helped to shape your life and how important it was to have experiences with all people growing up and how you think that really led to a lot of strengths for you, both in your career and for your current role as a caretaker. So, do you have any advice for parents who maybe aren't DSPs, but they've heard your story and they think, you know, they want their kids to have those inclusive experiences, do you have any advice for them, or any encouragement?

Rachel: Okay if there were parents out there who aren't really connected to our field, I guess what I would say is something that a lot of people I think on this podcast have already said, and that's just you know open your eyes and reach out because when you really look around you, you start to see people for who they truly are as our fellow brothers and sisters and you stop noticing those differences as much. But you can't do that unless you've had exposure to them so I guess what I would say is, you know, try to be friends. You know, go out of your way to befriend people who are different than you and learn about their lives and their experiences and their challenges and try to find out what their gifts and their strengths are, because they truly do make your life richer having a diverse group of people and friends and connections in your life. So, don't be afraid to reach out and don't be afraid to ask questions, because knowledge is power and the more knowledge that we have about life and how the world works and each other, that's the only way that we can truly grow as human beings.

Colette: Awesome. I think you just gave some great advice. Thank you so much for joining us today and sharing your story and your words of wisdom with everyone.

Rachel: You're so welcome! I'm so happy you asked me on here and you know I love to talk about myself and what's going on, so I was happy to zoom with you for a little while.

Colette: Great. We'll put everything in the show notes and if anyone does check out the blog or anything like that let us know, send us a little note on the *Building Buchanan*; we've got like a "contact us" thing and let us know what you found on there and what was helpful for you. We would love to kind of hear which resources really resonated with you.

[Energetic music]

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