

Seizing Life, episode 48
A Disability-Friendly Model for Independent Living
Guests: Jillian and Scott Copeland
(Transcript)

- Kelly Cervantes: [00:00](#) Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by Citizens United for Research in Epilepsy, CURE. Today, I'm excited to welcome Jillian and Scott Copeland to another remote version of Seizing Life. Jillian founded the Diener School in 2007. The school is a nurturing yet challenging environment for students with learning differences. Jillian served as the head of the school from 2007 to 2013, the chair of the board of trustees for the following six years, and now serves on the board of trustees.
- Kelly Cervantes: [00:42](#) Scott has been an active developer and builder of affordable housing for over 20 years. He is a principal with RST Development, a development management and construction firm that predominantly serves moderate to low income households, is also a former CURE board member. Jillian and Scott are the parents of four sons, Danny, Jack, Nicholas, and Ethan. Their third son, Nicholas was diagnosed with epilepsy at eight months old. When Nicholas was a teenager, the Copeland's began contemplating his life as an adult and investigating the options available for their son.
- Kelly Cervantes: [01:14](#) Their experiences researching adult living options for Nicholas motivated their latest project, an ambitious reimagining of community housing for adults with special needs called Main Street. They are here today to talk about how their search for an appropriate living environment for Nicholas led them to found Main Street and how this project differs from other housing options. Jillian and Scott, thank you so much for joining us today. I cannot wait to share with our audience about Main Street, this incredible project that you guys have been working on for several years now, you just had the ribbon cutting for this amazing, amazing building. But first I want to give you the opportunity to share about your inspiration for this project, your son Nicholas. Tell us about his journey and what brought you to Main Street.
- Jillian Copeland: [02:07](#) Hi, thank you Kelly for having Scott and I on the podcast today, we're excited to be here and hopefully share something that brings some hope and inspiration to other people. So, our inspiration for Main Street was our son Nicol, who is now 21 years old. He's really excited because he gets to put a splash of ram in his diet Coke. He started having seizures when he was eight months old. His first seizure lasted longer than two hours and he's had subsequently, I don't know how many, maybe 100, 200, many, many seizures over the years requiring several

hospitalizations for testing. And I'm sure everybody on this call knows the drill, lots of different medications and interventions and schooling and different doctors and different opinions.

Jillian Copeland: [03:00](#)

And I'm sure again, you all are not unfamiliar with this. And we really spent some time thinking about and researching what his life would look like when he became an adult. And it looked as if a lot of folks out there with developmental disabilities, medical challenges, special needs, weren't living a life of meaning and purpose and passion. And we spent some time looking around to see what was out there. And although there are many amazing programs out there and we visited physically and virtually many of them around the country, Nicol didn't seem to really fit into a lot of them. He thrives in inclusive environments.

Jillian Copeland: [03:40](#)

We found that there wasn't a lot of affordability out there for many people and that seemed to be a major issue and a barrier for people who wanted to live independently. And we decided, we can give him this and hopefully bring a lot of other people along on this journey with him and provide spaces and opportunities and programming and hopefully a change of mindset so that others can be a part of Main Street, those with disabilities, those of all abilities.

Kelly Cervantes: [04:12](#)

Transitioning care is such a huge concern for parents. We've talked on this program about transitioning from pediatric to adult providers, but I think one piece of it that is so often overlooked is quality of life and housing. And this idea, these adults are then forced to stay in their parent's home and don't have the opportunity to connect with others and to have the support they need to live these full lives. How is Main Street providing that opportunity for these individuals and their families?

Jillian Copeland: [04:58](#)

There are so many issues affecting or impacting adults with disabilities. I hope that Main Street brings the gestalt, brings everybody together. And that's what I find is a big challenge. Not only are employment issues a problem, 50% of people in our county that have disabilities have jobs, only 50%. That's the highest rate I have found around the country. There's also, right, there's not a lot of affordable living, so people have to be in their parents' homes as you said. And then what happens is there are programs that are out there, but they're very siloed. And there isn't a lot of collaboration amongst professionals that I have found in the disability space.

Jillian Copeland: [05:43](#)

And they also, I believe that once we can allow people to continue to learn, right? So, once they reach the age of 21 and

they hit the cliff as I'm doing using air quotes here for people who cannot see, all eligibility, all entitlements are ceased and then you become eligible for programs, but it's a long process to get there. And it is this difficult transition from high school or post high school to becoming an adult. And so, everything is piece meal and nothing is collaborative and easy. And what happens is because of these lack of opportunities and because you really have to fight for everything including funding, you are already tired. Your parents are already tired. The adults with disabilities, some of them aren't self advocates. Some of them aren't able to have their voice heard. And so, it's easier to play video games in your basement. And therefore, you create this cycle where you have a disconnect from community.

Jillian Copeland: [06:48](#)

In our county, one in three people with disabilities, adults with disabilities have said they had no community connection within the last year. And this was prior to COVID where many of us aren't having community connections. So this isolation for both caregivers, whether it's siblings or family or parents also feel this disconnect. And what happens is this isolation turns into depression. It turns into loneliness, it turns into anxiety.

Jillian Copeland: [07:13](#)

And so, we feel at Main Street that providing opportunities for inclusive members, inclusive people of all abilities to come together, to share common interest, to share common goals, whether it's social skills groups, or we all enjoy music, truck lovers, car lover, sports lovers, chess lovers, people who love art can come together, share with each other, provide opportunities to learn and to grow and to socialize and really to have a place to belong.

Jillian Copeland: [07:42](#)

And then once people feel self worthy and have this sense of self efficacy, perhaps they can apply for different jobs. Perhaps they have better skills. Perhaps they have this confidence that allows them to go out into the world and find opportunities for meaning and purpose and passion. And some of that really starts, Kelly with kindness and just providing a place to belong. And that's really what we see Main Street already doing even before this flagship building is open.

Kelly Cervantes: [08:17](#)

I think you hit on something so important there, and it was brought to my attention during a previous episode that we did with Sherry Brady. She emphasized the word belonging over inclusivity. And I saw in the video for the ribbon cutting that you were, in one of the pictures you're holding a sign that says belonging. And I think that word, it speaks to me in such a deep way, because yes, we want to be inclusive, but this idea that the disabled community should already be included. They belong in

the world with all of the rest of us. And it is us neuro-typical abled body folk that need to realize that we don't need to make space for them. They belong here just as much as we do. And I think that that is such a beautiful part of this project.

Brandon: [09:17](#)

Hi, this is Brandon from Citizens United for Research in Epilepsy or CURE. Epilepsy affects 3.4 million Americans. Learn more about cutting edge epilepsy treatments and research at cureepilepsy.org. Now back to this episode of Seizing Life.

Kelly Cervantes: [09:34](#)

Getting down into the nuts and bolts, what is the building? Who lives there? How do people apply?

Scott Copeland: [09:40](#)

So, the building is a 70 unit apartment building. As Jillian mentioned, we really ran it on three major pillars if you will, one was affordability. The other was inclusivity and the third is sustainability and that's both from an environmental and in a building standpoint, but also from the sustainability of all the phenomenal programming that will happen in the building. So, in addition to the 70 apartments is 10,000 square feet of community space. We have a great fitness room. We have a peace room and a classroom and a kitchen that's named after my father-in-law, Jillian's dad called Poppy Boy's kitchen, which is a great teaching kitchen, a catering kitchen, and a great living room, where we have a huge TV and just nice little gathering spaces.

Scott Copeland: [10:39](#)

And so, the goal is that not only will the residents of the building get to enjoy everything that's happening on the ground floor, but also members from the community that don't live in the building, unfortunately it's only 70 apartments and the demand is through the roof. There's just such a huge, huge need for it. So way back when, at the very beginning of this, Jillian's brainchild was to make sure that we were able to include others from the community that wouldn't be able to live there. So, that's exactly what's happened.

Scott Copeland: [11:14](#)

So, it will be a membership based activities that will happen on the ground floor. Obviously COVID has put a little bit of a damper on the timing of it, although the pivot into the virtual platform that Jillian and our team we're doing now has been really vibrant and really fantastic stuff. So, but when we get back into some physical opportunities, I think the building will be just full of programs and all different sorts of things. And as Jillian said, all different sorts of people being part of it. So, it's really exciting.

- Kelly Cervantes: [11:48](#) So for the 25% of the units that are reserved for adults with additional needs, what are the requirements to be able to live in those units?
- Scott Copeland: [12:01](#) The 25% of the units that are set aside for people with needs, it's a difficult one in terms of a qualifying measure because it's loose in terms of how you would qualify. It's not any specific need per se. So, and I think that's why candidly, that it's just been so overwhelming because unfortunately there are a lot of people that do qualify for those types of units. So, it's not a problem filling them, I can tell you, the problem is, is that we just can't build enough of them is the biggest issue.
- Kelly Cervantes: [12:42](#) To that extent, are there plans to expand and to build more Main Streets? Because the demand is there, these options aren't available in most people's communities.
- Scott Copeland: [13:02](#) The hope certainly is to do more for sure. One of the things that we've focused on from the beginning is again the sustainability of the program, and to create as many opportunities as we can. And how this has come to be for us and for our family and for our community, it may be different for somebody else, but the opportunity to do more, to try to partner with other developers that may have an affordable component already built into their project, and perhaps we can persuade them to reserve some units for people with needs that can help expand the mission, I don't know to support in any way that we can, anybody else in their community that may be doing this, it's tough. It's a lot of work. I mean, it's certainly a labor of law. There's no question about it. It's a very rewarding process. But the short answer is yes, we hope to do many more and be a support for those that want to do something like this in their own community, which I think [crosstalk 00:14:13] a lot of support.
- Kelly Cervantes: [14:14](#) Yeah. And I think that there are, whether it's the programs or logistically, there is an opportunity here, you have built a model that doesn't exist and hopefully people can learn from that and even just know that something like this is possible, something like this can exist and they can use this to create their own similar space.
- Scott Copeland: [14:40](#) The real estate piece of it is daunting at first to build a building, and it's what I do, it's what our business is. But I think, really the secret sauce is the programming and the inclusivity and as you pointed out the belonging. And it's amazing how the mission was translated to so many different people at the very start of this, and it went across every person we met, subcontractors that were building on the project. When you told them a little

bit about what was going on there, hey, that would be great for my neighbor's son or my nephew. And it's amazing how it just goes straight across the board. It doesn't matter where you come from, it doesn't matter the color of your skin. None of it matters. It is a pervasive issue that most people or a lot of people can identify with.

Scott Copeland: [15:33](#)

So, while the construction piece is a daunting task, for sure, for some, I think that the opportunity to do something like that and to tie in the programming and stuff and to have that place of belonging, is really what makes it breathe and tick. It's really, that's critical piece to it.

Kelly Cervantes: [15:55](#)

Now, I want to talk for a moment about the staff. Are they medical professionals, are they trained? What is their background?

Jillian Copeland: [16:06](#)

So, that is a great question. So, we have two different structures here. One is the Main Street apartment folks, that is Scott's team and they run the apartment building just like they would any other apartment building. And then there's the Main Street connect team, which is my team. And right now we have nine people on staff. Our mantra here is a little different, Kelly than most models around the country. So typically when you move into a space that's identified for people with special needs, the housing and the services come together. So they're provided as one.

Jillian Copeland: [16:41](#)

So if you choose housing, whoever is their staff is your support service person. We don't provide any direct service providers here at Main Street. So we have no, what our state calls them DSP, is direct service providers. We do offer a scaffolding of staff and supports and assistance. But if you require, we actually have a mantra, we call BYOI, one of our members coined it for us and it's called bring your own independence. And that means Kelly, if you were going to live here at Main Street, and you have a two bedroom apartment, and you need full time staff for it, because you have mobility or cognitive issues, you bring in that staff person with you, you live in that apartment with your staff person.

Jillian Copeland: [17:25](#)

If you come down to our programming and you need some assistance there, that staff person can come with you or a family member can come with you. We have people on the floor all the time. If we have a yoga teacher, for example, teaching yoga, we also have a Main Street staff member in there. So if someone is having a medical issue, or if someone needs some help deescalating or regulating, we are trained and can do that.

However, we don't provide any one-to-one supports, and we only have the basic medical CPR and first aid training. So we are three blocks from our fabulous Rockville fire station number three.

- Jillian Copeland: [18:01](#) In fact, the head of the station was over here last night doing a training for our residents on how to be safe and where the egresses are. So, this mantra of bring your own independence allows people to have an apartment just like they would rent an apartment in any other apartment building. They have the key, it's their apartment. They can decorate design how they want. They come and go as they please, we have security in the building. And then we have people that are obviously on the floor when our programs are happening. We also have two community coaches that live in the building and for a fee, people can pay for their services.
- Jillian Copeland: [18:36](#) And again, it's a scaffolding of support. It's not one to one, let me help you do your laundry. Let's put food on the table, kind of a thing. That's not what they do. They meet and they help meal plan for the week. And they look at the weather and they talk about ... Help them with basic executive functioning issues. But if people require more support than that to live independently, then they bring their own support with them.
- Kelly Cervantes: [19:00](#) It's opens it up, I think, and makes it more available for folks if-
- Jillian Copeland: [19:09](#) It does.
- Kelly Cervantes: [19:10](#) And it also, it teaches a level of responsibility that [crosstalk 00:19:14]-
- Jillian Copeland: [19:13](#) It does.
- Kelly Cervantes: [19:14](#) Are living in mom and dad's house, and just the status quo remains. I just, I can't even imagine the sense of pride and independence that comes from learning these skills that may come naturally to you or I, but take dedicated training, that executive function that you're talking about, but to be able to meal plan and to take care of yourself. And I mean those are incredible skills that a lot of these individuals might not learn otherwise [crosstalk 00:19:49].
- Jillian Copeland: [19:48](#) They might not. And the bottom line really is that people have choice. So if they move to this apartment and they don't ... If we had service providers, maybe they didn't click with that service provider, but they don't really have a choice when you live in

group homes, which are amazing, by the way, I'm a huge proponent of all different kinds of models that are out there. There are some that are solely for people with autism. There are farms and villages and lots of different kinds of programs, and I believe we all share similar missions, but we have different models and we need all these different models. So, people with disabilities should have a choice just like you and I do. We get to live where we want, how we want. And so, this is just another opportunity to provide choice and self determination for people who don't really have that opportunity.

Kelly Cervantes: [20:38](#)

Outside of just these apartment units, you have all of this community space and you have incredible programs. Tell us about the programs, and then I also believe that some of these programs are available via Zoom to folks that aren't in the building. How can people access that?

Jillian Copeland: [20:57](#)

Yes, thank you for that important question. So when we started Main Street three years ago, we started with a membership. We asked people to join us. We framed it as an inclusive community who wants to be a part. And within seven days we had 700 members who all wrote a check and sent by mail because our credit card processor wasn't up and running yet, which to us showed the great need and support of what we were doing. And by the way, I will talk about our programs in a minute, but I'm going to just mention this. We knew we wanted to build a building. We knew we wanted an apartment building, we knew we wanted a community center, we could have a larger membership that could impact more people. And so, we knew that was in the plan.

Jillian Copeland: [21:41](#)

However, the building of the community has been the most beautiful part of this. And I would say to anybody out there, build your community, ask people to join you. That's how you can really create the impact. And then you can move into, okay, what do we want now? So, I think we did it in the reverse way, in a sense, but we're so lucky to fall into this membership that has been life changing for us too and I think for many others. In terms of programming, when we started three years ago, we were doing biweekly programs. It could be anything from bowling to a CPR class to a nutrition class, to meeting for pizza or at a museum or a sporting event. And luckily we're right outside of DC, Washington, DC. So we have lots of opportunities here.

Jillian Copeland: [22:30](#)

And so, we would plan biweekly programs based on our members' interests and preferences and needs. And that was super fun. And then all of a sudden, like the rest of you out

there, the whole right, our world changed and we had to pivot and create a virtual opportunity. So, we started having virtues, a virtues program, a space for belonging. We also had a game day with Bingo and Trivia, and we started providing this freemium virtual opportunities. And then we decided, okay, we want all our members to join again. So we created a summer virtual membership where we have eight to 12 programs per week. Actually, Tuesday night, this is the last week of our summer virtual membership and Tuesday we have our talent show.

Jillian Copeland: [23:17](#)

So we have 10 different people that will be providing amazing talent. I'm sure it will be a wonderful experience. But we've had everything from beer tastings, we have weekly yoga movement classes. We also have had a travel and adventure series, a culture series where we visit different museums. We tour different gardens, we have different artists speak. We have an arts and crafts club, a chess club, a sports club, and those are all member led and executed. So we have lots of different kinds of opportunities for people to join us.

Jillian Copeland: [23:49](#)

We have a program on peace and resiliency during COVID that will probably continue to be peace and resiliency just every day, because we can all use that. And we're adding a bunch of new programs for our fall. So we're going to add Zumba. We are also going to have a Black Lives Matter event and a couple other community opportunities for everyone to join us. So, if you want to be a member, our members get to be virtual, right? So you can be anywhere you are. We have people from all over the country that are joining us right now. We have 200 members and it's super fun stuff because we really have built this virtual community where people feel connected and they feel they're engaged. And during COVID, that is a difficult thing, I think for most people, but especially for our disconnected community of adults with disabilities.

Jillian Copeland: [24:38](#)

So, it's really been a wonderful experience. And I get so excited, I do the travel series and the movement. And then one other program I'm on every week baking with Sharon, which is super fun and I made a great chocolate cake. Well, mine wasn't as good as everybody else's, but it was still delicious. So lots of opportunities for people to join us virtually. And I'll tell you, if you join us, I promise you, you will enjoy and learn.

Kelly Cervantes: [25:04](#)

What's the site? Where can people find out?

Jillian Copeland: [25:07](#)

Everything from soup to nuts is on our website, which is mainstreetconnect.org. You can view our virtual ribbon cutting, which I think is pretty inspiring. You can also see our lineup of

programs that we have, and then we will have our fall membership, which should be up in about two to three weeks and it will start in mid-September.

- Kelly Cervantes: [25:26](#) You two are amazing, you are a powerhouse couple. This project is so inspiring. I remember Scott sharing about it at a CURE board meeting at one point, and just being so thrilled and maybe a little daunted [crosstalk 00:25:43].
- Jillian Copeland: [25:44](#) Right, right.
- Kelly Cervantes: [25:45](#) But I have to say it is just so exciting to see it come to fruition, to know that you have residents living in the building and that this dream became a reality and you are changing the lives of 70 units of people. And that's pretty remarkable. Thank you for all you both have done for the epilepsy and the special needs community, what you will continue to do. You are incredible advocates and allies, and we're just so grateful to both of you. Thank you. Thank you for chatting with us.
- Jillian Copeland: [26:22](#) Thank you for having us.
- Scott Copeland: [26:23](#) Thank you, Kelly and thank you for everything that you do. You do amazing stuff, thank you so much. It really, you move the needle, it's good stuff.
- Jillian Copeland: [26:30](#) You do. And we so appreciate it. We are there with all of the listeners out there who have epilepsy, whose children have epilepsy and we're with you and CURE going to find a cure one day. And in the meantime, we're all going to live our best lives and we're here to help you guys do that. And we know you're there for us, and Kelly, thank you so much.
- Kelly Cervantes: [26:59](#) Thank you, Jillian and Scott for sharing your experiences and for your amazing efforts to improve the lives of those with special needs. CURE has supported epilepsy research for over 20 years, raising over \$70 million to support more than 240 research projects in 15 countries. Still, at this time, researchers face unprecedented challenges requiring special protocols and equipment and unanticipated costs. For that reason, I am honored to share that CURE is launching the Epilepsy Research Continuity Fund to support scientists whose research is most vulnerable.
- Kelly Cervantes: [27:31](#) This fund will make \$350,000 available to researchers with active epilepsy studies to help them continue their work during the pandemic. Now more than ever, these researchers need our

support to continue moving forward towards the ultimate goal of a cure. We invite you to help support epilepsy researchers by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.

Brandon:

[28:02](#)

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