

Three Young Adults. 22 Years. Transitioning from Pediatric to Adult Medical Care

03/10/2019

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Series introduction

Throughout my 45-year career in health care I've been attracted to boundaries, the cracks between those boundaries, and have found myself drawn to welcoming people as they cross the threshold between those boundaries and cracks. Healthcare professionals often refer to silos. The silo of cardiology, the silo of surgery – silos by specialties. Then the silos of setting – hospital, home, clinic, long term care, emergency care, intensive care. Then the silos of professions – doctors, surgeons, nurses, therapists, then “other” professionals – social workers, acupuncturists, chiropractors. So, you see where I'm coming from when I say boundaries and cracks. Well, I'm a fixer by nature. Not the Michael Cohen variety of fixer but making it better. And the opportunity for better can be found at boundaries and cracks. These boundaries are never going away. It's a product of specialization. To be expert in something you need boundaries. “My specialty is within these boundaries.” Therefore, fixing can be found when we treat boundaries as thresholds and welcome people across thresholds.

In my experience, one of the scenarios with the most boundaries, cracks, and thresholds is where young adults with complex medical conditions transition from pediatric to adult care.

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So, welcome to the Health Hats podcast series about young adults transitioning from pediatric to adult medical care. In this series I will interview young adults with complex medical conditions, their parent or guardians, point-of-care clinicians caring for these young adults, and whoever else I find of interest in this fascinating, frustrating, heart-breaking, and inspiring world.

Podcast introduction 2:32

Welcome to Health Hats, empowering people as they travel together toward best health. I am Danny van Leeuwen, a two-legged, old, white man with privilege, living in a food oasis, who can afford many hats, and knows a little about a lot of healthcare and a lot about very little. Most people wear hats one at a time, but I wear them all at once. We will listen and learn about what it takes to adjust to life's realities in healthcare's Tower of Babel. Let's make some sense of all this.

Episode introduction 03:04

Health Hats

My first interview of the series is with Jill Woodworth, a mother of four who has three children with Tuberous Sclerosis. Tuberous Sclerosis Complex or TSC is a genetic disorder that causes tumors to form in various organs, primarily the brain, eyes, heart, kidneys, skin and lungs. It's also the leading genetic cause of both epilepsy and autism. I met Jill through her podcast, [TSC Talks](#). I reached out to her and we set up a two-way interview. You can find Jill's interview of me on her website. It's [Episode 28, Ripple](#). You can find these links in the show notes.

Please contribute 04:01

Please contribute to my blog and podcast help me maintain this ad free blog and podcast. I appreciate your readership and listenership. Go to my website, www.health-hats.com/support to contribute. Thank you.

Three Young Adults. 22 Years. 04:28

Jill Woodworth

I was reading one of your pieces about transitions. I really felt like you, wow, put to words a lot of my personal frustrations with managing the care of. I have three kids with tuberous sclerosis. I've been managing for 22 years.

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Health Hats

Oh, my goodness.

Silos and boundaries 04:48

Jill Woodworth

Yeah. Yeah. Nuts. I know it's a long story, but I just wanted to you know, I've had a pretty good sense of the fact that now I'm going to many different doctors to help them and many different social services and just constantly encountering disconnects is far as someone's getting treated for their kidneys from this doctor and then their brain over here and then they go to see a mental health professional over here. And if there's any communication, that has to go through me. Unfortunately, I have to network that system and that's just really cumbersome

Well, you know, I think like you said when the kids were younger it was a lot of crisis because seizures tend to be one of the earlier symptoms of tuberous sclerosis and getting those under control it's tricky. So that was the priority. So, I wasn't it burden and by, all the care of the multi-system, many silos as much. And also, it seems, like you said, the pediatric system is set up to really support far more integration and communication than, you know, once they turn 18 and then 21. And suddenly you're with this kid that pretty much has all these same needs that they had when they were a kid and then there's no cohesiveness and you're kind of steering the ship. So, I think that that's been my experience that especially with a condition such as tuberous sclerosis complex were by nature it involves many organs of the body including the brain to treat it requires a lot of silos and a lot of boundaries especially with the mental health piece of this particular condition. Though because 90% is the quoted number of people that have behavioral aspects of tuberous sclerosis says pretty much everyone. and the I think that's the biggest challenge after the getting the emergent, the emergency like threatening situations under control and you know managing the medical aspect once that's manageable which in some kids. God, I'm really grateful that my kids, knock on wood, are pretty stable in that area. But managing behavioral piece has been really eye-opening and really has prompted me to start a lot more advocacy and activism on behalf of parents out there dealing with these challenges their kids, you know, they've had in they've been managing this condition and suddenly their kids are becoming physically violent. And in some ways which was my experience, my son was quite violent, and we had to get a lot of Mental Health Services for him. And you get the mental health services, which are we were able to do thank goodness. We had a lot of people helping and I kind of ended up being a... Mass Health is great. They have a behavioral aspect to their support. So, I felt like I was able to get the support I needed here in Massachusetts. In some

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ways it was really difficult to then go back and translate that to his other doctors and his school system, for instance. I'm talking about my son who has the most behavioral challenges. Just because you spend a you take a kid and you get them treatment and he was in a community-based day support program or therapeutic treatment program and got a lot of help. So that I'm bringing them back into the school system and you know trying to give them the information. And as well as his doctors and what the meds are so then there's a psychiatrist at a TS clinic in Boston and there's a psychiatrist at a place out in Westminster where he was. And then there's the school people and I was spending all my time, really managing this and I you know, I haven't really had paid employment other than being an adult foster care provider for my daughter and hopefully again for my son. Yeah, so I've just been really vocal with the TS Alliance as far as letting them know how difficult and frustrating this is and that there are solutions. But I think that it needs to be looked at... Boy, it needs to really be looked at quickly as far as somehow roping in more of a behavioral piece to the TS clinics That's my kind of my part of my soapbox. [Yeah] but I don't know I could go on forever. I think you understand. I am so for sure.

Health Hats

How are your children? How old are they?

Jill Woodworth

Okay. I have a 22-year-old daughter who is yeah 22 and then my another one is 20, Sarah my daughter. Then my son is 17 and then I have a daughter that is 14 that does not have TSC.

Transitioning? The earlier the better 09:56

Health Hats

Okay, so and so how are you managing that transition for with your older kids into the adult...

Jill Woodworth

If I was joking around, I'd say, 'not that well.' But I've learned kind of backwards with my oldest daughter. She was in high school and she was getting ready to graduate and she had a lot of medical issues during high school. She had brain surgery. I was really managing a lot of other things. So, I wasn't paying close attention to her educational system. So, when she went to graduate high school. I had no idea what was going to happen because she would know we're prepared like a typical kid that we graduate high school and I don't think they're as prepared as they should be either. But I ended up advocating for getting her a post-grad year and I really kind of it was almost a little too much too late. She didn't get a lot of the behavioral support

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when she was younger. However, she did get them, and she is actually doing all right, I have to say but that was really eye-opening for me not to go, into too much detail. What my son might have. I have a 20-year-old who has TSC. She's in her second year of Community College and she is far less affected on a behavioral level or she's not on the autism spectrum. She's quite intelligent. She does have medical issues with some, you know, behavioral issues but minimal compared to my oldest daughter. And then my son who's turning 18 in May. I've been able to really be on top of his transition. So, I feel a little better. But it is it isn't like anyone is going to really help you. You really have to help yourself and you have to I've had to use a lot of Social Services. I have, mostly with Mary Ellen my oldest and then my son John, Jack we call him. They have DDS Services. They also have Mass Rehab. What else? Mass Health has been helpful. And so, you there's a lot out there but I had no idea where it was? Who to ask? How to access it. The clinic, the TS Clinic while there are wonderful clinic and you know, they are life-saving. They had no idea how to help me with that. They have a social worker there that really is probably more focused on the local area. And will I see the doctors in Boston in Mass General for the TS care? I also have doctors out this way for like primary care. So, you know, like he's just a multiple disconnects. Because I did it with my older daughter I kind of get what to do. I can help. I can also help other people that have questions about how to transition. I'm certainly not an expert. But boy, it is something that I wish I always say do it the earlier the better. The earlier you can think about it the better.

Primary physician who knows you best? 12:52

Health Hats

Transitioning. Do each of your children have one - I don't want to necessarily say primary care physician - but primary physician? So, one that knows the individual child the best and provides some assistance to you and them with that coordination?

Jill Woodworth

You know, when they were younger, I was going to say yes, I do. They have the same primary care physician who is a pediatrician and that's going to have to change. But she's in Worcester at a UMass and it was really necessary to have someone out this way, so I wasn't driving, you know, an hour and a half to Boston. I kind of care and she knows them to a degree. However again it then there's the clinic in Boston and our neurologist knows them probably the best of all. I would say the neurologist knows all of the kids with TSC.

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Health Hats

And is that a pediatric neurologist?

Jill Woodworth

Yes. However, they do treat now, they're taking adults at the Mass General TS clinic. So okay, which they haven't, you know, that's a learning curve for them. So, I feel like I'm kind of teaching in some ways, as well as asking for help a lot. And they're very willing and a lot very willing. I think they know that there is more that's needed.

Autonomy. Meet them where they are 12:52

Health Hats

So, one of the things about transitioning from pediatric young adult to adult, is the autonomy. The individual autonomy. So, it sounds to me if I'm hearing you right that there are medical and behavioral challenges. With that autonomy transition depending on their cognitive and behavioral baselines. So how as a parent, do you deal with that?

Jill Woodworth

Their own autonomy? Then okay. Well my oldest daughter was on the autism spectrum. She is in a shared living situation, which is worked out really well for us. And she is slowly working towards some autonomy. However, due to the, you know, it has to be baby steps and she has a caregiver who's I got lucky in that situation and found one that really understood autism and is willing to work with me. But I spent most of this past year that lovingly training this provider and then she's taking the ball and she kind of gets the idea of she understands my daughter well enough to pick up the ball and start teaching her. It's just a very delayed autonomy. Now. I don't know whether she'll ever be fully capable of managing all of it herself and I would say she would she try in my opinion. And no, I would never... Miracles keep happening. Things unexpected happens. I've to go with the fact that right now, I don't know what she'll ever be able to. But then my son. I should say my 20-year-old daughter will definitely be able to. The one that's in college and she's already starting to she manages her medications which was. When I'm teaching her. I'm like, I've been managing this for all these years. I made it... Like I do a lot of it in my head and to teach somebody else and then see their frustration with pharmacies and disconnects with MassHealth or whatever insurance is been eye-opening. So, I'm really seeing some gaps there where she's, you know, she's emailing the doctors now and not getting a response. Or she's calling the pharmacy and getting the answers and really having to teach her. But I think she'll be able to do it. But it's me teaching her and again, probably a bit delayed.

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Yeah, and then my son, he will be able to do a lot for himself. But again, it'll be very slow. Yeah, he's cognitively the most affected most. I would say to a degree because his behavioral issues were not really addressed until, in the way they should have been until he was in his teens. So, he lost a lot due to behavior. Unable to really access any curriculum because he was so behaviorally impaired. But I had to be I'm very hopeful because he's made great progress once we got that piece, kind of, I don't stay under control because there's always challenges. But he's learning. Like I taught him to get his own meds, you know, it's kind of meeting each one of them where they are and what they can do. So, but it's hard.

Health Hats

Oh, yes. My hat's off.

Is there hope for the system? 18:01

Jill Woodworth

Oh, thank you. Yeah, you know, I don't. I wouldn't do anything else, but it may it really motivates me to try to understand. Like you really have an in-depth from your work and lived experience of the... and being at all the different jobs that you've had in the Healthcare System. It sounds like you really have a lot of inside understanding how things work and why they're frustrating and yes. You know, what is hopeful. I mean, do you have hope yourself?

Health Hats

Depends on what minute you ask me. You know, the one hand. I have for the medical industrial complex, I would say I have very small hope. My goals are my goals are small and you know, I'm old enough now and seasoned enough that my goals are to move the needle 3 degrees. [Yes] On the other hand, I have great hope for small groups, small communities, people such as yourself, somebody who has a lot of lived experience who is an advocate for others in your community and I think there's tremendous power in that. So yeah, that's all sort of a half-assed answer.

Jill Woodworth

But well, not really. I think that it's hard to know really in a lot of ways how quickly change is going to happen. But I it seems really like we're deeply entrenched in this medical industrial complex and it's going to be like you said moving the needle a few degrees.

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How do you find a minute? 20:06

Health Hats

How do you have a minute? So how do you find ten minutes to be an advocate? And now you have a podcast and a website and sounds like you're doing quite a bit of support and advocacy. How did you find that?

Jill Woodworth

I think when I started. when my daughter moved out my oldest daughter I was. That transition of getting her into shared living consumed a lot of my time. I'm so I finally and also just the emotional energy I was putting into care and she required more caregiving and the other children. And I so when she left there is some... I don't want to say a void, but I had a little bit of space and I felt really like I needed something. I almost went back to a full-time job. I looked into case management. And just at the last minute, I knew that if I did that at that at the point where I was I would be putting my own mental health in Jeopardy because of the juggling. I just I've done it for so long that a lot of it is just second nature. As far as their medical care and like I can pick up something happens I know exactly what to do from a medical standpoint even behaviorally now. There's time during the day and when I can devote to you know, particularly the podcast which is really where my energies are focused right now and hopefully, I'll be able to make it lucrative in some way. But yeah, I'm kind of giving all over the place.

Your own health 21:40

Health Hats

Well, that's good. I mean so, how do you how do you take care of your own physical mental and spiritual health?

Jill Woodworth

Well, I got a good package for you. Okay? I'm a runner. So, I run just about daily. I've done, you know meditate. a firm believer in physical activity. I think that it's a variable that a lot of people that are on a lot of meds or you know, really have other restrictions that if they can. I'm an advocate of moving in whatever way possible. So yeah, that's pretty much what I do. I have people connections that I can get some like comic relief and venting and you know support small support group. The TSC Community is quite devoted bunch of people and very, very close-knit. that's been helpful to as far as managing it. but you know, I like I said, it sounds like a lot more than it looks like because I have been doing it so long, so. Yeah, and but I do hope to be able to

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use it for like to help other people as they navigate their way. And right now, that to me it would be to me the podcast is brilliant idea to just let people here or how difficult this can be for caregivers what challenges they're facing as well as then having guests in to address some of those concerns, so. I am I absolutely love doing it and it gives me something to put some energy into. Though, I am I am stretched. I am always stretch. Yeah. Yeah. I'm sure that you understand that.

Health Hats

Oh, totally. Well Jill, it's been a pleasure talking to you. Thank you so much for your time. Okay.

Jill Woodworth

Yeah great, Danny. Great to talk to you and meet you. Take care. Bye. Bye.

Fascinating, frustrating, heart-breaking, and inspiring 23:45

Health Hats

Wow. See what I mean? Fascinating, frustrating, heart-breaking, and inspiring. What is Jill's super power? Love, persistence, energy, humor. I'm humbled by the capacities of the human spirit. I have interviews coming with three young adults and their moms. They're different and the same. Stay tuned to this Health Hats channel.

Follow my blog and podcast 24:11

Follow my blog, podcast, and resources through my website. See you around the block!