Podcast

Autism Conversations

UNM Autism Programs

Autism and Aging
Podcast Transcript

Debbie Montana:

Hi everyone and welcome to Autism Conversations, a podcast by the Autism Programs at the UNM Center for Development and Disability. I'm Debbie Montana and I'm a program specialist with the autism programs. I'm honored to be here as your facilitator for today's podcast titled Autism and Aging. Today I will be talking with Elisheva Levin, a Self-advocate, and Judy Greenfeld and Chinda Lucoski, both parents of aging autistic children. Please help me welcome my friends and colleagues. Now we're going to begin with a brief introduction. Elisheva, could you start us off, please?

Elisheva Levin:

Sure. So, my name is Elisheva Levin and I am an autist, but I didn't know it for many years until, um, my son was diagnosed, um, at the age of seven here at the center for Development and Disability. And so that's how I found out that I was on the spectrum. I'm also, uh, a late bloomer, so I got my PhD when in, uh, let's see, it would have now it would have been 2017. So, I finally finished all my degrees and everything, but I was late, as I said.

Debbie Montana:

Thank you for sharing. And would you like to go next?

Judy Greenfeld:

Judy Greenfeld and my son Ricky was diagnosed as being on the spectrum when he was three years old at the University of Denver. And at that time, we were very fortunate because there was a visiting professor by the name of Leo Kanner, who was one of the very first people to put a name to autism. He did that about ten years prior to the time we got there. So, we were very lucky about that. But Ricky is going to be sixty-nine next week, and he's very excited and tells everybody. He's very verbal, has many of the characteristics of autism and has gone through so many different, categories or I don't know how you would list it, but as a child he started out walking on his tiptoes and shaking his fingers, and Doctor Kanner knew immediately what was going on. Anyway, we've gone through lots and he has lived in an ARCA group home for the last forty-some years, so he will be talking a little later.

Debbie Montana:

I love that. Thank you for sharing. And last but not least, Chinda.

Chinda Lucoski:

Hi. Hi, I'm Chinda Lucoski. I'm here from Alamogordo, New Mexico, and I'm originally from Bangkok, Thailand, and I was immigrant here fifty years ago as an exchange student, and I met my husband in college and we got married for fifty years now. My daughter, who has autism, she is forty-six years old and she is considered as level two. She was diagnosed as autism when she was about eight years old. You know, with lots of labels, you see whatever you have. But anyway, uh, she is definitely is intellectual, developmental disability slash autism slash, uh, cerebral palsy. But anyway, all of that is not nothing is just a label. She is working almost full time at the ability one program at the Holloman Air Force base. And also, on the weekend work at Ihop, okay, as a food service assistant. And, uh, she is very, very active in the community. And I'm very grateful for all the support people helping me here in Alamogordo. Thank you.

Debbie Montana:

That's wonderful. Thank you for being here, all of you. Uh, we appreciate you being here to discuss a much-needed topic that is important so that we know how to support aging autistic individuals. So, let's begin the conversation. Elisheva, I would like to start with you. Can you share with us how you stay socially active? And is it harder now that you're older?

Elisheva Levin:

Yes and no is what I would say. Um, so I have never been an extremely social person. Um, I don't like big crowds generally. Um, although I make some exceptions for certain things like holidays and things like that, but, um, but I like to know when I'm in that kind of crowd. What exactly is going to happen? And, um, I spent a lot of time trying to figure out why all these people are doing, keep talking, and then they'll walk away from you when you're in the middle of a sentence or how I guess we would say you know, non-autistic people think. And, um, so I like to be with people, but I don't really want to be with huge crowds. And so as I've gotten older, I've become more like that. Um, I did make an exception last week and, and went to a holiday that we have. Um, and it was, it was raucous. But you know, I sat in the back and kind of, uh, made myself comfortable and there were people I hadn't seen in many years that I had the opportunity to see, so that was awesome. So, I would say that that's, you know how I do it, but I also limit myself. I know when I need to leave now. Um, I used to weigh out, do my limits and then be just shaking by the time I got home. So, I like small groups, and I like friends, and I love the fact that we have internet because I can talk to people and not have to go somewhere, not have to drive, do all those things. I do a fair amount of driving and I love driving in the wilderness, but I don't much like driving into it. That makes sense?

Debbie Montana:

You know, I know firsthand that, you know, when we age, we need to modify how we keep active. You know, I know I don't do the same type of workout that I did in my twenties, my thirties, or even my forties. I found that at this stage in my life, yoga and walking is much more forgiving of my aching joints. So, I think that's just right.

Elisheva Levin:

Walking is, is, is the best exercise, I believe.

Debbie Montana:

Absolutely. So, um, I'm going to direct this question first to Chinda. Chinda, have you found any health care challenges as you or your daughter has aged? And what would have helped?

Chinda Lucoski:

Well, it is challenging, especially right now because the turnover from the healthcare providers, I have to seek the one that comfortable and have some knowledge about autism and feel comfortable with her. We're changing the new providers right now from a female to male, and, uh, it is a, it's a, it's a task, you know, to educate him to say, this is how my daughter is and this is what she wants. And without him being kind of, uh, I can feel, I can sense that he's not comfortable because he didn't have any experiences, you know, with developmental disabilities or especially the high functioning ones. It is ongoing, but, but I get used to it now. And this is a small town and I'll be able to do some searching and talking, to feel comfortable, to see how they feel. So, everybody is different. So that that is just interviewing and, you know, keep looking for the one. Even physical therapists and massage therapists and we change all the time. So, so just try to find someone that my daughter's comfortable with.

Debbie Montana:

That makes sense. And what about you, Judy? You found the same type of challenges?

Judy Greenfeld:

We do have a lot of problems with health care issues because, um, turnover of physicians, as Chinda just said, um, finding somebody who understands autism, although I'm really lucky because Ricky enjoys being with doctors and I think it's the one on one and they're paying attention to him. And he particularly likes females and he likes women staff. He does not like men staff. And we found out why years ago he was abused in a private school. But he responds very well to doctors and questions as best he can. And if they direct it to him, it works really well because very often physicians will talk to the parent instead of the individual. Um, I don't know other than the fact that if we could just find healthcare individuals going right now, we're waiting to hear from UNM labs about a scan that's supposed to have been done for Ricky a month ago. That's our main problem.

Debbie Montana:

That's unfortunate, I know facing healthcare challenges is something that has unfortunately become the norm for everyone. And I think, I think all we can do is just hope for positive changes as we move forward. Right? Um, what about you, Elisheva? I was hoping that you could have some insight on this topic.

Elisheva Levin:

Yeah, I, and I do because, um, I have some significant healthcare issues that I had all my life. Um, I would have been blind, considered legally blind, except for that they were able to, um, you know, even in those old days were able to see that I could, I could see. But I mostly was hearing in school for a number of years because when they're not paying attention to, uh, you know, issues, I don't know whether to continue. Yes, please. Okay. Um, when they're not paying attention because you're a bright kid, but you have some significant challenges. Um, you can get lost in that. And so because I was sitting in the front of the room, because I was so short and I was short kid in my class all through grade school and I, um, so I had glasses all my life, pretty much. And, uh, I have to go now and get shots in my eye, my right eye every two months or so, but that it sounds horrible. It's not as bad as you think because I can't see it. You know, I'm sure my husband would faint, but I can't see it. But the thing about it is, is that what I see there is in that kind of service, I'm seeing a lot of change that's going to be good for all of us. But on the regular side, I also have a different experience because we were so very rural for so many years and we're still rural. Um, so, you know, Catron County is one of the frontier counties in New Mexico. And getting health care services usually means driving across state lines. Because my husband, you know, worked and then retired from Sandia National Labs. We are able to do that. Um, but I worry a lot about people in, in our part of the world who can't because they have to get services because of Medicaid in their state. And I just think we need some

kind of national system, so that, you know, everybody can get the services they need because like for us, we're eleven miles from the state line with Arizona. And, um, the, the little towns right over in Arizona have very good health care. The one thing about rural health care, because we're under CMS is and that you'll have to tell them what it means because it's not coming out of my mouth right now, but, but because um, you know, we get better health care in a lot of ways than you do in this city. So, I go home to Arizona now. We have a house in Arizona. My husband worked after Sandia, um, worked at the mines down there. And we, um, we get that same kind of rural health care right in Safford, Arizona. And I can see the doctor the next day, usually if I'm sick enough. Wow. So that's another thing where it's like, hey, we get this. Why doesn't everybody get this right? Right.

Judy Greenfeld:

Can I add something to these? As Ricky has aged and been on so many medications, he has developed tardive dyskinesia, which I don't know that everybody is aware of, but he does a lot of shaking, a lot of jittery movements. His legs, his hands, his tongue. Um, and we have just recently been told there's a possibility that he has Parkinson's due to a lot of the medications. And this is something that folks who have disabilities run into frequently because they take all the medication. And he was on quite a few things for psychological reasons. Um, many have, not many, several have been discontinued, but he still has the symptoms. And that's one of the reasons we're waiting for a scan to make sure what's going on in the brain. So, this is something that, um, the medical situation is holding up for us and the lack of medical care.

Debbie Montana:

Well, we wish him all the best. Thank you. Ricky's very important to us. Yeah. Um, we're going to go ahead and move on to the next question, but I appreciate the elaborate responses. It's very helpful to those that are listening. Uh, let's see, um, what supports do you, excuse me, what supports does your daughter wish maybe that she had right now or that you wish she had, but that you can’t access for her because there's a lack of adult support?

Chinda Lucoski:

Well, at this moment I don't see anything because she has everything she needed, you know, to be functioning well in the community. And because we on Mi Via program self-directed, she'll be able to find her own caregivers and support. And right now, I have four staff on review for her, you know, so we job coaching and community access and, and a home homemaker, which is me, you know, at home as I take care of her. So, and she's I don't see any she needs it at this moment because we fulfill everything she needs at this moment.

Debbie Montana:

That's wonderful. That's really good to know. You're very fortunate. And thank you. What about, um. What about you, Elisheva? What supports do you wish you had right now that you can't access? Because there's a lack of adult supports?

Elisheva Levin:

There is a huge lack of adult support for those of us who are on the spectrum and we do need help. We do have differences that need to be addressed because we don't get services. And then you go to going on Medicare was a nightmare. I mean, that program has probably not changed since nineteen sixty-six. I looked it up because I was so frustrated, and I don't see and think about things in the same way that, you know, I guess what you know, you'd call non there's a name for you guys, but typical. Is it neurotypical? That's right. It's neurotypical. Thank you so much. And so, the problem is, is that I need directions. I need them visible

because I do have problems with my eyes and they're going to get worse. And some of this does come from autism, by the way. There's a lot of things we don't know about how that changes our brains. But I do know that that was this huge nightmare and I finally had to throw a fit. I now understand why people on the spectrum throw fits. I had to, you know, call up Sandia National Labs because that's where we're getting our healthcare from. You know, sort of roundabout way. And, um, and tell them that I needed guidance because if it's not there on that page, I don't know where to go looking for it. And I would suspect that a lot of us who are on the spectrum, but who do not, um, you know, rise to services at all. Um, we're in the same boat and I suspect we're in the same boat with a lot of other people who maybe are neurodivergent as well because of how we think. It took me three days, um, with like twenty-five phone calls and some of the people were fairly, you know. I mean, I tried a Mac for example, and the guy was just like trying to tell me, no, uh, you know, you don't have to do this and you don't have to do that. And I'm like, you know, I would like to have the Medicare because, um, very, very wealthy people don't have to get Medicare. People in Congress don't have to get Medicare. But we do because that's the thing we're counting on for our, um, for the rest of our lives, basically. So, you know, these are, these are big problems and I get that. But there is no reason that we can't be doing something about them as a country. Um, so I have the same feeling for that as I have about, you know, the fact that you can't cross a state line and get services. And both of those things have to change. We're not back in the, you know, early nineteen hundreds or late eighteen hundreds anymore. And people, you know, are we can we can move a lot further.

Debbie Montana:

Yes, ma'am. You are right for sharing that.

Elisheva Levin:

I appreciate that. Well, thank you. It's, it's my mission. I I'm already working with people up in Santa Fe. Wow. I got so mad I called.

Debbie Montana:

Yeah, you watch. It's gonna one day make a big difference. And yes. Judy, what about you?

Judy Greenfeld:

Yeah. We need more supports and people who are working in group homes because the turnover of staff, just like in the healthcare industry, it's tremendous. And people with autism and people with other Developmental Disabilities, um, depend on knowing who's going to be at their house at what time and when to expect them, and what to expect that they will do for them. And this is really tough for people with autism because more than others, uh, I know that they expect certain things and they look for certain people. And my son is able to read, and he can read the calendar and he can see who's supposed to be there and doesn't show up, which happens very frequently. And then it's very hard to make a plan to what are we going to do with Ricky today because he only likes to do three or four or five different things, and the individuals do not know our people when they get there. There are substitutes. So, this is a big problem at the group homes.

Debbie Montana:

That breaks my heart. It's. It reminds me of the time when Ricky worked in our department, and, um, I, I was fortunate to be one of his, staff helpers, and I loved it. We had the rhythm, um, of what, what he was going to do. And I could tell when he was off for whatever reason, could be medication or he just could have been something may not have shown up.

Judy Greenfeld:

He may, you know, you just never know. But he loved working at the CDC and he knew exactly what he could do. And then Ricky has, quote unquote, retired because not only did he, he got tired of it, but they couldn't find, uh, programs and, uh, tasks for him that would fit his needs.

Debbie Montana:

I do remember some of it. He would get a little. He was very funny. I would say, do you want to do it? And he would tell me, no, I don't feel like it. Yes, ma'am.

Elisheva Levin:

I just wanted to add from what you said, because I think it's really important that one of the biggest problems for us as we are aging is that there's nothing for us. You know, in the old days when they talked about how the kids fell off the cliff and they still do. Well, now we have not only, you know, young adults who are just starting out falling off the cliff. We and we also have people in their midlife phases, um, that we don't, you know, they don't have anything to do or they, they don't know what's out there or there is nothing out there. But also, those of us who are aging, there is a huge cliff. It's like, okay, you're sixty-five. um. And if you can't work, what do you do? Uh, because there's nothing. We, we thought about kids, you know, who were maybe very, very young, but we need to realize this is a life-long disability or set of disabilities.

Debbie Montana:

We're going to go ahead and move on to the next question. But before I do that, I just want to say that, you know, I really think that this podcast is just the beginning. You know, I'm hoping that it ignites a fire in the minds of those that, that are listening and that provide autism-based supports because it doesn't just end here. I'm hoping that we're creating a buzz and that and that we are opening a door to possibilities for our future aging folks with autism. That's what I'm hopeful about.

To start us off with our next question we are so lucky to have Ricky Greenfeld who will share with us what he finds enjoyable about adulthood and retirement. Ricky is an adult with autism and Judy's son. I have known him for many years. We worked together at the CDD up until he retired. He also has his friend Rita Crozier with him today.

Debbie Montana:
How have you been?

Ricky Greenfeld:
Just fine. It's been a while.

Debbie Montana: Yeah, it's been a while. What have you been up to since retirement?

Ricky Greenfeld:
Doing things with Anna, like going to the Dollar Trees.

Debbie Montana: Awesome! Do you buy things when you go there? Like, what type of things do you like to buy?

Ricky Greenfeld:
I'm not sure, like, some kind of snacks.

Debbie Montana:
You and I are too much alike. Gotta have the snacks.

Ricky Greenfeld:
No dairy.

Rita Crozier:
No, you're good at that. You're very good at staying off.

Ricky Greenfeld:
Stay off the others, right?

Debbie Montana:
Always been flexible, from what I remember.
Are you enjoying retirement?

Ricky Greenfeld:
Yeah, I'm enjoying retirement.

Deborah A Montana: Really?

Ricky Greenfeld:
I'll tell you, my birthday is March 23rd. I can hardly wait to be sixty-nine.

Debbie Montana:
Sixty-nine! When did that happen? I must have been when I was sleeping.

Rita Crozier:
Every year in March, huh?

Ricky Greenfeld:
Every year in March. That's right.

Deborah A Montana:
I can't believe that.

Ricky Greenfeld:
I'm telling you, we'd like to go to the Barnes & Noble, maybe to the Hobby Lobby.

Rita Crozier:
When we're at Barnes & Noble, what do you want to see there?

Ricky Greenfeld:
See what they have there. I'd like to get something that's different.

Rita Crozier:
Okay. A game? A puzzle? Books?

Ricky Greenfeld:
Maybe a little puzzle.

Rita Crozier:
Okay. How many, how many pieces are the best?

Deborah A Montana: I think I like sixty-four.

Rita Crozier:

Okay. Sixty-four. That's great. Good, good.

Debbie Montana:
Do you still like tigers?

Ricky Greenfeld:
I still like tigers.

Debbie Montana:
Nice. Do you get to go to the zoo at all?

Ricky Greenfeld:
Orange tigers, not much. I got to do that with my brother, Bob. My mom told me that Mike and Bob and Kimberly and Vicki are coming for my mom's birthday party.

Rita Crozier:
That's wonderful!

Ricky Greenfeld:
I like your new glasses.

Rita Crozier:
Thank you, Ricky. I like seeing, too, so it's good that they're yeah, they're bigger. They're bigger!

Deborah A Montana: Ricky, what do you like to do for fun other than going to the bookstore or to the zoo?

Ricky Greenfeld:
I like to do paint by number.

Debbie Montana:
Really? Are you working on one right now?

Ricky Greenfeld:
I'm gonna start to try. I like looking at pictures on computers. I like the bird launching plywood puzzle, the math puzzle, and I like other pictures.

I'm gonna have to tell that to Melissa tomorrow.

Deborah A Montana:
I remember when I worked with you, we used to listen to music, certain songs that you liked, and we would sing together.

Ricky Greenfeld:
There was a song that I can't remember. What were the names?

Debbie Montana:
We used to listen to Mamas and Papas. We used to listen to, think it's called the Age of Aquarius.

Ricky Greenfeld:
Yeah, I like the Age of Aquarius.

Debbie Montana:
You still like that song?

Ricky Greenfeld:
Yeah.

Debbie Montana:
Every time I hear it, I think of you. I used to love singing with you.

Ricky Greenfeld:
That's about the fifth dimension.

Debbie Montana:
Yes, the fifth dimension.

Rita Crozier:
Awesome. And what about Maria?

Ricky Greenfeld:
Maria, the West Side Story.

Rita Crozier:
That's right.

Rita Crozier: Who composed West Side Story?

Ricky Greenfeld:
Leonard Bernstein.

Rita Crozier:
That's right.

Ricky Greenfeld:
It's L-E-O-N-A-R-D.

Rita Crozier:
Leonard.

Ricky Greenfeld:
Leonard. L-E-O-N-A-R-D.

Rita Crozier:
Yes.

Ricky Greenfeld:
L-E-O-N-A-R-D.

Rita Crozier:
How is Bernstein spelled?

Ricky Greenfeld:
B-E-R-N-S-T-E-I-N.

Rita Crozier:
How many records do you have of the West Side Story?

Ricky Greenfeld:

Probably about 4. I have a picture.

Rita Crozier:
Yeah, we're not going to get any more of those.

Ricky Greenfeld:
We need to get something that's different. I know I got one of Al and Sherman that I found with Anna.

Rita Crozier: Oh, yes. I love Al and Sherman.

Ricky Greenfeld:
I'd like to get one of Harry Belafonte.

Rita Crozier:
Oh, yes, that one.

Ricky Greenfeld: I like the one that has Shannon Doah.

Rita Crozier:
Banana Boat song, too? Do you like that song? Day-O.

Ricky Greenfeld:
Yeah, I think I like Day-O. It's different. Day, oh, day. I like the one by Bob Gibson.

Debbie Montana:
Oh, okay, okay. Bob Gibson, I'll write that down and look it up.

Ricky Greenfeld:
I like the one that has There's a Meet in Here Tonight, Day O, the Big Rock Candy Mountain, Clementine, let's see, Marching Across the Green Grass, Billy Boy, Daisy Bill. Let's see, Joshua, the battle from Jerry Kong, All Through the Night.

Deborah A Montana: You have a really good memory still. I remember that about you.

Ricky Greenfeld:
I like that record about high fidelity.

Debbie Montana:
Oh, okay. Very cool.

Rita Crozier:
Yeah, that means you're able to listen really well in a high fidelity.

Ricky Greenfeld:
They look great, right?

Debbie Montana:
You haven't aged at all. You look the same. You do look great. I was noticing that.

Ricky Greenfeld:
It's been a long time.

Debbie Montana:
I know. It has been. When did he retire?

Rita Crozier:
Well, I could look up the pictures, but I can't remember. Yeah. I think it's Two years! Yeah.

Ricky Greenfeld:
Two years I retired.

Debbie Montana:
Yeah. Well, you look fantastic.

Ricky Greenfeld: I look fantastic.

Debbie Montana:
Yes, you do! That's because you are fantastic.

Ricky Greenfeld:
I am fantastic.

Debbie Montana:
You absolutely are. I have always thought that. I think that's why I miss you so much being here at the office. So, I would consider you my friend, who, who are some of your other friends?

Ricky Greenfeld:
Or my other friends that when I worked here? I still remember, like, a Federa and Felicia. We forgot to order me, a green and yellow, kaleidoscope thing. I haven't seen it on the computer yet. You don't have it on your cell phone, right?

Debbie Montana:
I don't think so, I'm sorry.

Deborah A Montana: We could try looking later.

Ricky Greenfeld:
Can we try looking later for a tour, right?

Debbie Montana:
That'd be okay. Yeah.

Deborah A Montana: Do you still talk with Mary?

Ricky Greenfeld:
Yeah, I talk with Mary. Mary Kay.

Debbie Montana:
Okay, awesome. What about Mary Jimmerson?

Ricky Greenfeld:
We haven't heard from her. She's got another job.

Rita Crozier:
Yeah, I know. She's been busy. She's always been a busy person.

Ricky Greenfeld:
She's been a busy person.

Debbie Montana:
Yeah, with Trey.

Ricky Greenfeld:
Trey's not a kid anymore.

Rita Crozier:
Not a kid anymore. Trey's not a kid anymore.

Ricky Greenfeld:
We go to, Barnes & Noble. We'd like to look for some kind of a CD-like. I can't remember what the names of the songs are.

Rita Crozier:
Okay. Well, you'll remember by the twenty-sixth.

Ricky Greenfeld:
I'd like to have the twenty-fourth.

Rita Crozier:
Twenty-fourth, oh, thank you, thank you.

Ricky Greenfeld:
I'd like to get me another, word search.

Rita Crozier:
Okay. Sure.

Deborah A Montana:
Ricky, because, we heard that your birthday is next week, like you were just talking about it.

Ricky Greenfeld:
Next week. Can’t hardly wait until I be 69.

Debbie Montana:
Oh, me too. That's awesome.

Ricky Greenfeld:
But my mom says, remember, Ricky, don't ask for anything, right?

Rita Crozier:
Well, she does say that, yes. That's okay.

Debbie Montana:
We brought you some cake,lemon cake, and lemon bars, and let me see about strawberries, and Dr. Pepper.

Ricky Greenfeld:
Where are they at?

Debbie Montana: We're gonna pull them out right now, and we're gonna invite some people to come over join us. So, I'm gonna go ahead and set up.

Rita Crozier:

So, people are gonna come here, and you're gonna get to have an early birthday party.

Debbie Montana:

Thank you so much Ricky!

Alright, so our next question is, Chinda, what are you or your daughter finding to be enjoyable about older adulthood?

Chinda Lucoski:

That's a good question. Well, it is it is difficult to keep her happy all the time. You know, at least I can make peace at home without meltdowns and all other anxiety issues. Okay, to take those aside, you know, I would say preparing for, uh, to be structured, you know, what's the next event coming up? Like she'll enjoy dancing and singing. So, I make sure that she had social activities lined up for her. On what day? What time? So, she will prepare mentally, you know, to go to dance, to sing. And I felt like when she came home, she's so happy and her self-esteem is much better because she sang, you know, in a group. And even though it was off key, but it to me, I feel like, wow, she had the courage to do that. So, it made her feel acceptance, you know, in the group, in the events. She just go everywhere, in the church communities in the Buddhism prayer meeting, and in the autism adult groups. And, she's party at work. They have party almost every month. for pizza for whatever. So, you know, socially, that's what they need because they, feel like they need to be learning from other people and learn how to speak up for themselves. So, this is a very good opportunity for them to try. So, allow them to go, and encourage them and prepare them. That's all I would say.

Debbie Montana:

It's beautiful. Thank you. Thank you so much for sharing. And what about you, Judy?

Judy Greenfeld:

Oh, Ricky enjoys shopping a lot. That's one of his main joys he likes. Excuse me. He knows the dollar tree. Every dollar tree in town and the thrift stores. And he loves music. He'd like to go to more musical performances. He enjoys the zoo because the tigers are his favorite animals. So, if he could go see the tigers and the birds, he's a happy guy. Unfortunately, though, he has somebody with him two hours a day, twice a day who can take him somewhere. And otherwise, if he's home and I cannot get him involved in something, he stays in his room listening to his CDs or sleeps. And this is another issue. It it's very hard to find things for older people. And he is, he's almost sixty-nine. And you have to keep busy other than lying on your bed.

Debbie Montana:

That's right, that's right. Thank you for sharing. And Elisheva, what do you find enjoyable now in adulthood?

Elisheva Levin:

Oh, a number of things. My kids are raised and, um, and so that's very good. Um, but I would say that the, the thing that I enjoy most is watching the millennials and getting them to help me. For years and years, I didn't ask for help. But when you get to a certain age, they know you're old and so and they know that the world has changed. Um, or at least you can tell them, hey, the world is changing, I don't know what I'm doing with this program or I don't know how to call and do this because I want to call on the phone and talk to a person. How do I do this in other ways? And, um, and so there, I've been enjoying the millennials a lot. And I'm really enjoying watching the millennial autists, and the experiences they have that maybe we didn't get. But at the same time, I'm also seeing the same kinds of prejudices and attitudes. And so that's something that we still have to continue to work on. So that makes me feel good too, because I enjoy having that work. And right now, I do a lot of work at the DDC, the Developmental Disabilities Council. And, uh, we're, we're

bringing in some new ideas maybe that will help the people coming up after. And that also makes me feel good to be part of the community, so, um, I need to kind of repair my community and other places, but, um, but that at least is going strong even after the pandemic.

Debbie Montana:

That's awesome. Thank you. Elisheva. Thank you. Uh, you know, I just want to add that for any individual, aging is seen as the transition in time of life that finally allows you to live authentically and comfortably in your own skin, right? So, you can now focus on what makes you happy rather than conforming to external societal expectations, right?

Elisheva Levin:

Can I make a comment about women? One of the things is, as a woman, my whole life, you spend a lot of time trying to appease men, and you spend a lot of time trying to appease older people. Um, all of that is gone. I tell them exactly what I think and they get to hear it.

Debbie Montana:

That's great. You don't hold back.

Elisheva Levin:

No. maybe there's something about that. And I went through menopause very late. I just finished, uh, five years ago. And now finally, I don't care. It's a wonderful feeling. Yes, I don't care. Right.

Debbie Montana:

Well, good for you. Um, I guess to wrap it up is, um. Chinda, what advice would you have for the community as we close?

Chinda Lucoski:

Well, the community have helped me a lot with Alicia because to me, everybody knows Alicia in town from every store and from what she growing up in this community, especially a small town like Alamogordo. And this is where she's going to be retiring. And then while I'm gone, she's going to be living here. So, I just want to make sure that she's comfortable with the location, you know, how to move around navigation and what. How to make appointments for everything she needs and people knows her. So to me, it's ongoing, but it's much easier now compared to twenty years ago. People, because of autism awareness and everywhere people talk about autism. So, so people learn more. And especially with Alicia being part of the LGBTQ, you know, communities, it is a little bit challenging, but it doesn't, it doesn't bother me or her as much, you know, because she's like I said, she's comfortable in her own skins and, and she's happy. That's what, that's what it's count, you know. But I want to mention something regarding healthcare challenges, uh, because right now I am involved with the aging and long-term care, especially for me. Okay. I'm thinking about what happened to me when I'm no longer here. And that's a big question. And if I'm still sound minded, you know, without dementia or anything like that, because those are aging related. And since we work so hard all our life, you know, taking care of autistic individuals and maybe our brain just exhausted. So, I really want to have the, the, the, the research on individuals with developmental disability and Alzheimer. You know, where, where can, can, uh, where can they be placed or what happens? Uh, because this is a specialized training, okay? Not just regular caregiver can take care, uh, elderly care. But with challenging behavior, they change, they turn into infancy or whatever those, those need to be addressed, you know. And I want, really want to see caregivers get that kind of trainings, you know, for them in the future.

Debbie Montana:

Amen. I agree. How about you?

Judy Greenfeld:

I totally agree with what Chinda said. I had thought about education for the community and I don't know how that gets out there. People say to me, how come so many more people are on the spectrum, if you will? We hear more about more people and more people with autism. And I think part of that is because sometimes they don't, the medical community doesn't know where to place our developmental disabled people, so they put them on the autism spectrum. Uh, that's just my own observation, but we need to educate our communities a lot more, as well as the people who are working with our folks.

Debbie Montana:

Thank you so much, Judy. And last but not least, Elisheva.

Elisheva Levin:

Well, I want a world in which everything is in vanilla and chocolate. In other words, I want a world where everybody belongs and has a place to belong and where there's some understanding. Because a lot of my faux pas through my life, and I've had many, um, because I don't see the world, you know, in typical fashion, I guess you would say. And a lot of that just, it wasn't that I was trying to be difficult. It was that I have to balance my, um, my own brain and I have to be able, I, I'm not going to come across in the same way all the time. I mean, I can do it for a while, but then I have to go rock. Okay. So, um, I would like to see the community become even more aware. And it's interesting. When I did a research project for the CDC that we, I found lots of people like the people we're talking to here today who are aware because they have children or because they're on the spectrum themselves. But there are so many people that don't understand that when I'm fumbling for my purse, it's because I can only think of one thing at a time. You know, I focus, for example. Or that maybe someone is slow. So there, we need not only, places like UNM has done a great job down at the campus, finally of getting rid of those horrible stairs that I fell down several times. Um, you know, those kinds of things are starting to get fixed, but we also need people to recognize that where it isn't bad. It doesn't it doesn't scan that way. Yeah. Um, so that's what I would like to see for the community is, is more, um, more awareness of the individual. Every individual has their quirks, right? So, but when you get a label, those quirks become something of a permanent record, right?

Debbie Montana:

Thank you so much. On that note, I would like to just say that on behalf of the Autism Conversations Podcast team, I would like to thank our panelists for joining us today. I also want to thank you, the listener, for tuning in. If you are interested in hearing more of our podcast, we invite you to check us out at our local Autism Programs portal, Spotify, or wherever you get your podcasts. Until next time. This is Debbie Montana reminding you to keep the conversation going. Take care.