Webinar: Abundance of Love: Parents of Autistic Children, Teens, and Adults Share What They've Learned

AutCom Presents:

FREE ONLINE WEBINAR: SATURDAY, APRIL 29TH
ABUNDANCE OF LOVE: PARENTS OF AUTISTIC CHILDREN, TEENS, AND ADULTS SHARE WHAT THEY'VE LEARNED

Register Here

Registration in Advance is Required*

11:00am – 1:00pm ET | 10:00am – 12:00pm CT | 9:00am – 11:00am MT | 8:00am – 11:00am PT

Moderated by Lisa Lieberman, MSW, LCSW is an Oregon psychotherapist in private practice with over 45 years of experience.

Marie Giongo

Sara Arshad

Danielle Vauthy

Dennis Mashue

Sharon Koeppl-Medina

Paul Bakeman

Visit www.autcom.org to learn more about Autism National Committee

We are pleased that we can finally release the transcript of this webinar with a parent panel sharing what they have learned, held in 2023. We deeply regret that we were unable to preserve the video to upload to our website, but we have the transcript and hope that it will be interesting and informative. We have made some edits for continuity and readability. It starts with introductory comments and personal insights by AutCom Board Member and webinar host, Maxfield Sparrow. The webinar moderator, Lisa Lieberman, presented the questions to the five parents on the panel and also spoke from her own experience as a parent.

1. How old was/were your autistic child(ren)/adult child(ren) when they were diagnosed and how old is/are they now?

2. Has your view of autism changed as a result of parenting an autistic person? How? Has your view of parenting changed as a result of parenting an autistic person? How?

3. If you could send a message back in time to yourself at the moment you learned your child's diagnosis, what sort of advice and information would you share with your past self?

4. What are some things other people said or did for you or your child that you are especially grateful for?

MAXFIELD SPARROW, AutCom Board Member and webinar host: Hello everyone and welcome to our second webinar of the year. My name is Maxfield Sparrow, an autistic adult and I have not raised my own children. My understanding of parenting comes largely from having been parented. I want to talk to you for a minute about my dad who was very clearly autistic but never diagnosed because he came from a time when only autistic people with the very highest support needs were recognized.

I learned a lot about parenting by being parented by him. My dad was a very good father and he was a human being who make mistakes. The first thing I want to tell you about that I learned from him is it's good for a parent to apologize to their child. It was hard for him to apologize to me and it was hard to hear him apologize but I accepted it and I treasure the memory of his willingness to be vulnerable with me. Let your children see you being human.

I struggled growing up and my father supported me through many of them but there are other struggles that would trigger something in him. For example, I would hear him shouting in tears over my handwriting. The shouting was his and the tears were mine. My handwriting was awful and all the stress we went through together did not fix my penmanship. It did not occur to me at the time but his handwriting was terrible as well, too. Of course, my cursive writing was even illegible to him. He was getting triggered by me for not been able to do something he cannot do either. That was when I learned the second thing that I want to share about parenting. Parents get triggered because of love and fear. My father loved me, and wanted me to have a better life than he had.

When he saw me having the same struggles he had and making the same mistakes, his fear for my future would grow and sometimes, even affected the things he wanted to do or say from a place of love. No matter what he chose to do, though, I don’t think my handwriting would be great. If I want to write something legible now it's slow and I approach it like I'm drawing the letters.

I wish dad was more patient with my dysgraphia though. He apologized to me in my twenties and for all the battles we had over my handwriting. It was easier to forgive him because all my life, he let me see him as a real, flawed, loving human. Even though I never parented my own child, I tell you what makes for a good parent because I was raised by my daddy.

Listen to your children, believe them, validate their experiences, create a safe place for them to express who they are without fear of being harshly judged. Be willing to be vulnerable sometimes with your children. Be human, apologize when you've gone astray and remember to let your love be bigger than your fear.

The parents we have assembled in this panel will have far more impactful things to say because they have been actually raising children for years. Some of these parents are people I know, and respect deeply. Others are new to me and I'm eager to hear what they have to say because I know I'm going to be developing deep respect for them as well as, too. I know people who invited these parents to be here today, so I know we will hear from some high-quality human beings. I will leave you with this thought: yes, you absolutely must remember to let your love be bigger than your fear.

And love alone is not enough. To parent well, you need love and you need community. Never stop listening to your children, listening to autistic teens and adults, listening to other parents, never stop thinking and learning. No one is born automatically knowing everything they need to know to be a loving and effective parent. Never judge yourself harshly because you did not know something. Keep listening and learning because being the parent your child needs and deserves, is a lifelong journey. Thank you. I will turn it over to Lisa.

LISA LIEBERMAN, Moderator and parent: I'm a parent to a wonderful 34-year-old man, Jordan. He prefers person first language, although that may not be my first choice. He's a man with autism. He is turning 35 next month and for about the last six months I've never been able to say it out loud, and he told me to get over it. Anyway, I'm honoring Jordan by being here today, and I'm also a clinical social worker. I've been in private practice working with people with different kinds of differences on disabilities, which is my specialty. Most importantly, I was on the board of the Autism National Committee for years. My own situation prevented me from continuing to be directly involved, but it's always been close to my heart.

It's nice to see a few familiar faces here. I know there has been a big changing of the guard. We will get started. By the way Max, I love what you had to say. I was taking notes here. Really beautiful points that you made. I took them to heart as well as the parent. Thank you for that. So, we will start with the person who has the youngest child with autism. That would be Danielle Vauthy. So tell us about how old your son was when he was diagnosed and how old he is now.

DANIELLE VAUTHY, Parent panelist: Matteo was diagnosed when he was 12, in the middle of the pandemic. He is about to turn 14. When he was eight he was diagnosed with ADHD inattentive. So, it's been about five years of challenges trying to assess what he needs. When he was 12, he was fully diagnosed with autism.

LISA LIEBERMAN: You haven't had all that much time to get used to the diagnosis, but how has your view of autism changed as a result of parenting Matteo?

DANIELLE VAUTHY: My mom is an augmentative communication specialist. She did her graduate work when I was growing up. I was always with her during that time, so I've been around autistic people in the community since I was little. I also went to her classroom when she was teaching. I had an understanding of it but I didn't live it. So, I understood it from more of the teacher perspective and the daughter of a teacher. It's definitely different when you live it. It's definitely not scary when you live it. When you get a diagnosis of anything it's the unknown that is scary.

I think it's just become a part of his personality and who he is. I definitely do. I have two other children, and we parent children differently based on their needs, whether or not they have a diagnosis. It's just part of his personality, and, being a parent, you really flex. The most important thing is flexing based on what your children needs. I think what's changed is I realized it's part of who he is. And he will have different needs and I will have to be having varied expectations. Just like every child, they all have different needs and expectations.

LISA LIEBERMAN: So, you went to the second part of the question. What I hear you saying is you learned that parenting needs to be very individualized to the needs of our children. That applies for all children. How has your idea of parenting changed in this time? How has your view of parenting changed as a result of parenting your son?

DANIELLE VAUTHY: I think I went into parenting thinking I had all the answers. I thought I could figure everything out. I would describe my parenting style when I first became a parent as defined "by the seat of my pants." I will address things as they come, I'm smart, I figure it out. I realized with neurodiverse children and all our children for that matter, that being very deliberate and thoughtful and anticipating and setting them up for success are so important. You know, just having structures, expectations, and boundaries which I didn't really have. That was a huge learning curve for me because it really changed the way that I operate in the world. You know, without children, you can kind of fly by the seat of your pants and you can get by but with children, you really need to have a plan. You really need to set up your children for success.

The other thing that really changed for me is that I stopped looking at parenting as a sprint but really as a marathon. I think initially, I would look at an individual issue that we were having, or difficulty, and I would try to problem solve my way out of it, and so I would miss the forest for the trees. So, we are really seeing my son bloom, and he is really starting to socialize and find his place in the world. I don't know if I would have ever been able to get to that point if I didn't take a step back and take a breath and know this really is a marathon. I'm going to be his mom for the rest of his life and I'm going to be supporting him for the rest of his life. It is not just that one moment. Giving yourself perspective and giving yourself a lot of grace and give your children--your child--grace is so important.

LISA LIEBERMAN: Beautiful. What I am hearing is, I think, is that maybe it would have been less structured, less boundary setting in terms of your comfort level, but this kind of forced you to re-create -- forced you to regrade your parenting style.

DANIELLE VAUTHY: It really did and it was really hard (Laughs)

LISA LIEBERMAN: Next, we are going to go to Dennis Mashue. How old was your son when he was diagnosed?

DENNIS MASHUE, Parent panelist: Tucker was 2 ½ when he was diagnosed with PDD-NOS, because back then, no one wanted to come out right and say autism. About age 4, he got the formal diagnosis of autism.

LISA LIEBERMAN: He old now is?

DENNIS MASHUE: 24.

LISA LIEBERMAN: 24! OK. And maybe you could address how has your view of autism changed in 22 years?

DENNIS MASHUE: One thing that has happened in the 22 years is about 18 months ago, I was diagnosed as autistic with ADHD. What I came to believe, the more that I interacted and met other autistic people, I came to understand that autism is really a positive quality if you can figure out, as my friend Dena put it, we don't grow out of autism, you grow into it. -- Grow into it. I see a lot of positives. ADHD is a little matter that is a little bit more difficult. I learned to see that most autistic people that I know seem to be very intelligent. I think that is a big positive that is not always seen. That would be the biggest change for me.

LISA LIEBERMAN: Of course, we have different definitions of intelligence.

DENNIS MASHUE: Right.

LISA LIEBERMAN: We all know how worthless the IQ tests are for a lot of this population but, I mean, my son has incredible emotional intelligence and sensitivity. OK, and then, how has your idea of parenting changed as you grow into your own autism and your son's?

DENNIS MASHUE: When my son was 14, 15, I was 50. That was when I came to the understanding that there was a genetic component. I came from Michigan, which still is kind of in the dark ages with regard to understanding autism and neurodiversity. It has been a long learning curve. My view of parenting changed and that, I think it is important for parents to get over ourselves when we understand that we have a child with autism. And even if you don't have a child with autism, being a parent is not . . . it is not about us! The goal should be to raise good humans as whatever type of human they choose to be. The way autistics explain it is to meet them where they are, take their hand, and walk beside them.

LISA LIEBERMAN: That is interesting because I am thinking about what Max said earlier about showing our humanness to our children and sharing our errors, and maybe that is not contradictory of what you are saying, maybe it is a different dimension. It is something, when I'm working with parents of autistic kids or autistic adults as well, I coach them to start showing their own human foibles. In that sense, it is not always about the child or the adult with autism. I don't know if that makes sense, so often, they continue trying to parent rather than allowing themselves to go to the developmental steps that we have to go through as parents, in order to accommodate our kids as they develop. There is kind of a balance between, it is not about you and yet at some point, I think it is really helpful for them as they become adults, to become aware that their parent is also a human who makes mistakes and has needs.

DENNIS MASHUE: Absolutely. I think one of the most important things we can learn in that process is, yeah, we are going to make mistakes and after we make mistakes, let's sit down and talk to our child about what mistake we made and that we apologize and we are trying to have better behavior. You know, just like we would expect of them, we need to expect of ourselves.

LISA LIEBERMAN: So, Marie Giongo, tell us about how old your son was when diagnosed and now.

MARIE GIONGO, Parent panelist: Our son, Michael, is 30 years old, and will be 30 in a couple weeks, so if anyone wants to wish him a happy birthday. It is a milestone. He was officially diagnosed when he was 2 1/2 but we had started the journey much earlier, back in the day; fortunately, it wasn't as prevalent a diagnosis as it is today. It took a little while, initially.

I always kind of knew something . . . I was trying to figure out the puzzle piece. Something just wasn't right so I knew, as a mom, intuitively. I guess when he was a little over a year, my in-laws came to us and they said, "Hey, we think he may be hard of hearing." Because they knew a child who was hard of hearing, and Michael was exhibiting the same type of behaviors. He wouldn't turn when we called him, that kind of thing.

We had his hearing checked and eventually that led us to a developmental psychologist. He said, he can't make the formal diagnosis “until I see him at least twice and I’m really tracking his progress versus a one-time snapshot.” So, we didn’t start with him initially, but we did start right away on early intervention, which I am a huge fan of. I think it truly is a gift, to be able to get it the sooner, the better., whenever the diagnosis is made, and then the journey began.

He was officially diagnosed 1-2 weeks before Christmas. You know, I guess I will jump ahead a little bit but for the question where how it changed or your view of autism changed. Sadly, it was almost like we were given a life sentence and that . . . We were literally told, "We were sorry to tell you." We were pregnant at the time and they are like, "We are sorry to tell you that your next child is a boy." Why? He is a gift. We didn't process it that way . . . we don't look at it that way. Yes, it has been a long journey.

To me, autism is a word full stop. It is a way that someone sees the world. I don't care what you call it, it doesn't change the human being who is in front of me. It doesn't change who he is, what his gifts are, what his challenges are. It is the same way for all of us. I just look at it, we look at it as a word, where we needed to do that way.

LISA LIEBERMAN: Was he the oldest?

MARIE GIONGO: He is my oldest.

LISA LIEBERMAN: It takes a lot of parents years to know what you had found at the beginning. It is kind of remarkable, actually.

MARIE GIONGO: It is freeing for me because what some of the other people have expressed. You want them to have the best life, but for us, I think you realize the expectations that are put on you, and then your child, through a societal lens. So, for us, it was freeing, because those expectations kind of went out the door, and it really became focused on we wanted him to be the best. We have to backup our talk and we wanted him to be the best person he could be and help him find his potential.

When he was first diagnosed, we had a quote unquote expert, say to us, when I asked something about college and he/she was speaking about a 2 1/2 year old, and he/she was like, "Sweetheart, you will be lucky if he makes it to high school." Who are you to set his expectations? Now, he is so accomplished. You know, it is amazing! If we had listened to this person, what do they know? For us, it was being able to say, no, we are going to allow him to be the best. He wanted to be the best Michael. He had to figure out what made Michael up. My husband played professional sports so Michael was a big kid and people would look at him and say, "You want him to play football?" My husband was like, no, I want him to talk.

It freed us that way. It freed us for our other children because we were able to translate that to them as well. You know, I really look at it as a blessing. Do I wish the child to have some of the challenges he had? Of course not. I also think it makes them the people who they become. I am so grateful for him. It doesn't define him, it just let me know who he is and where he comes from. I believe we are all neurodiverse. You know? It is really our perspective.

LISA LIEBERMAN: So, you walked into that situation having not been a parent. And having now been a parent. How has your view of parenting changed as a result of parenting Michael?

MARIE GIONGO: I just think as for everything, it is really about seeing each of your children as human beings. I think it translates to the outside world as well. It is about seeing who they are and helping them become the best person they can become. As stated earlier, of course you're going to make mistakes but we always told our children, whenever we made mistakes, we were doing the best with what we knew at that time. We have always had your best interests at heart. It is really about making it about helping them find who they are. It is really about trying to make them the best people and prepare for whatever opportunity life was going to give them or challenges.

LISA LIEBERMAN: That is wonderful. I look forward to hearing from you when we get to the next question. Our next person is Sharon Koeppel-Medina. How old was your son when he was diagnosed?

SHARON KOEPPEL-MEDINA, Parent panelist: Chris had normal development up to 2 1/2, crawled, walked, speaking, and played with other kids and being social. And then all of a sudden, at age 3, things changed. He started losing his language and amounted to having a very limited ability to verbally communicate his wants, needs and thoughts, which was one of the hardest times for me. But I have two children, I was a single parent. I knew that it was going to be up to me to raise my two children. So at age 3, when he attended the screening at his local elementary school, of course he scored very low in expressive language and fine motor skills. But his receptive language was off the charts. I knew he was intelligent. I knew he understood everything that was being said to him, and anything he was exposed to. He was very confident.

I think I said that, but at age 3 he was diagnosed with pervasive developmental disorder. That was pre-autism. Later, at age 5 he was diagnosed with autism. He is now aged 40, just turned 40 this year. When we moved to Vermont, he started attending a preschool half a day. I guess that's when the first signs were noticed, that it was difficult for him to socialize, with other kids. He kept to himself, he loved books, because I read to him all the time--even when he wasn't even born yet. She [the preschool teacher] would find him off by himself reading a book.

LISA LIEBERMAN: I will interrupt you because I want to note that you had a lot of experience with neurodiverse kids prior, I'm assuming, because you've been a special educator for years. How did your view of autism change after his diagnosis?

SHARON KOEPPEL-MEDINA: I have to say, I worked with a lot of different children with varying levels of abilities. But I'd never worked with a person with autism before. Back then, 40 years ago, they were still saying that the diagnosis for autism, you know, was because of the mother. And then when he was finally diagnosed as having autism, I went to the medical library and read everything I could possibly read about autism. What treatments were, what programs would work and whatever. To be honest, I wasn't pleased with what I was reading. There was no mention of his ability level, only his disabilities.

He went to a preschool program and he was eligible on expressive and fine motor skills in kindergarten. Fortunately, we were originally from the Midwest. My brother was doing a sabbatical at UVM and came to visit when Chris was only about one-year-old. I fell in love with Vermont just like most people do when they come here. Little did I know I would have an autistic son, and little did I know what kind of education setting he would be offered. Luckily, Vermont was always an inclusive state since the closing of the only training school in Vermont.

LISA LIEBERMAN: Is your other child older or younger?

SHARON KOEPPEL-MEDINA: Older.

LISA LIEBERMAN: You had parented a less neurodiverse person and then you had your son diagnosed. How did your view of parenting change as a result of parenting him, after having a child previously?

SHARON KOEPPEL-MEDINA: I had to literally get myself inside his head. Watch all of his movements, see his behavior and speech. What was he telling me to do?

LISA LIEBERMAN: Is it different from what you are doing with your older child?

SHARON KOEPPEL-MEDINA: Absolutely.

LISA LIEBERMAN: How did that evolve for you from who you were as a parent prior?

SHARON KOEPPEL-MEDINA: I still believe I was going to make sure that Chris was offered every opportunity my daughter had. Fortunately, the elementary school was pro-inclusion and he was never in a special class. He was educated alongside his peers K-8. Then the big change for Chris was when he was in second grade, he had an assistant working in his classroom--Alan Kurtz, who I think many of you know. Alan was hired through Washington County services. He had heard about something called Facilitated Communication, Rosemary Crossley from Australia, and her work. He actually invited me to speak with him, to see if I would be interested in this for Chris. And what it could offer him. I could talk for hours about that initial time spent with Alan. But he had literally changed before my eyes.

LISA LIEBERMAN: I know Alan, I was on the board with him for many years and he is really a sweetheart.

SHARON KOEPPEL-MEDINA: It's funny because he came back two or three different times and each time, Chris understood what it was he needed to do. He moved from his finger to his upper arm in three weeks. They invited me to come. I was a teacher as well so I couldn't get off of school.

LISA LIEBERMAN: Thank you, Sharon. We will move on to Sara Arshad. Tell us about when you are child was diagnosed, and how old they are now.

SARA ARSHAD, Parent panelist: Yasmin was born in 1974 so she is 48 right now. She is our third child. Apart from having a grand mal seizure when she was six months old, she was a lovely -- lively, feisty, neuro-typical chatterbox. When she was three years old, she caught a seemingly mild version of the chickenpox along with her siblings who had a far more severe case of it. Of course, she seemed to be doing really well, no fever, no reaction really, until one evening she suddenly stiffened when she was standing on a stool to brush her teeth. She fell backwards. Fortunately, I was there and caught her. But, from that moment, her personality changed. She temporarily lost language for a few weeks. All language. She had temper tantrums for seemingly no reason, and from that day on, she had seizures. We were living in Italy at the time, and the doctors there were completely befuddled.

So we came to Boston, to Children's Hospital, and eventually she was diagnosed with temporal lobe seizures. Then there was a mention of possible encephalitis which may have caused the stiffening of the body. So, at the beginning, we thought we were dealing with a child with epilepsy. We therefore attributed all her behavioral issues to her medications. Eventually when Yasmin was about 5-6 she had a core evaluation and at that time she was diagnosed with pervasive developmental delay. The temporal lobe seizures continued along with continued trial and error to establish which medications would work best.

Then the temper tantrums continued. Eventually, when Yasmin was in her late teens early twenties, she gradually lost the desire to use her verbal language. And her teachers told us that she would not progress intellectually beyond the intellectual capacity of a 12-year-old. And so they basically gave up trying to teach her how to read and write. However, it was not until Yasmin was in her twenties that we first heard the word autism attributed to her.

LISA LIEBERMAN: How is your view of autism changed over the years?

SARA ARSHAD: So, I don't think there's any real singular definition or description of autism. I think the spectrum is so vast and undefinable. But I often think people make generalizations based on characteristics of a specific autistic person they may have met or read about, or seen on TV. In my own case, since the difference between labeling from epileptic to retarded, to pervasive developmental delay, to autistic has made no difference in my daughter's life or mine. So, I've generally tried to ignore these labels.

When her diagnosis was retardation caused by encephalitis, one doctor told me to remember that tardiness, which the word retard was based on, doesn't mean you don’t get there. It just means you get there at a later point. Eventually, the neurologist explained and compared the impact of encephalitis to a short-circuit which may have blacked out certain pathways of the brain, and that the brain would eventually learn new pathways.

I've come to realize that the doctors know very little about the brain anyway. And so, I would say, that sometimes labels are convenient. It was because of her label as autistic that she was invited to be a part of her research on facilitated communication, which gave back Yasmin a voice through typing. Also, an opportunity to show the world what a deep thinker she is. I don't think my view of autism per se has changed as a result of parenting Yasmin. I would put it that parenting Yasmin has taught me patience with a capitol P. What has changed is my willingness and capacity to go beyond that facade.

LISA LIEBERMAN: Is there anything more you want to talk about how your parenting changed? Since she was your third child, I think you said.

SARA ARSHAD: Yes, I would say that I had to give her a lot of focus because her physical needs were terrifying to me. The seizures were really frequent when she was little and she would actually go through periods of time when she was having a seizure every hour and she would be passed out on the couch. This is a four-year old we are talking about. I think my parenting was very different towards Yasmin because her needs were so different from my other two. Over time, I learned that I had to actually accept who she was and actually change my parenting towards her to set the same amount of limits on her that I was setting for my other two kids. That was a hard lesson to learn because I think I had to overcome fear of causing or precipitating a seizure.

LISA LIEBERMAN: Thank you. I am hearing a very overriding theme of, let's not focus on much of the diagnosis, let's focus on who this person is. Not just from you but from several of the panelists. Next, Paul Bakeman. it is really nice to see you. It has been a lot of years. Tell us when Jen was first diagnosed.

PAUL BAKEMAN: It was kind of undiagnosed (Laughs) in a sense. Jen is older. She is now 55 and next month, she will be 56, but not tomorrow—the end of the month. So, we entered the scene when the expert on autism was Bruno Bettelheim. That wasn't a very good expert. There is a very nice book about the creation of Doctor B. It turns out he was a total fraud. He claimed to be a psychiatrist or psychologist or something and set up these prison schools in the Midwest someplace. People thought he was the right guy. He was, you know, a psychotherapist, I think you could call it.

LISA LIEBERMAN: You had a lot of years to think about autism. Your beloved wife of blessed memory, I was with her for many years and I can only imagine how things changed for you. Are you able to articulate your view of autism now from earlier? Once you figured out what it was?

PAUL BAKEMAN, Parent panelist: Initially, you could use the label of autism and get services. We lived in New York State, and if you were labelled artistic, then the educational system wanted nothing to do with you. And they put you in the mental health bucket. They kind of wrote you off. So, it was not good to get a diagnosis of autism at that time. We got clued in by Rosemary Oppenheim, who was in the mental health department and she and her husband were very early proponents of the talking typewriter. It was before facilitated communication, but they used a typewriter machine for people with autism and got a fair number of them to use it. No one would believe it but you know, she steered us away. Jen wasn't officially diagnosed until she was probably six or seven.

LISA LIEBERMAN: Well, that's early for those days.

PAUL BAKEMAN: She was significantly affected, so there was definitely something that wasn't right.

LISA LIEBERMAN: How would you describe autism now versus what you may have thought at that point? I mean, just former than the latter.

PAUL BAKEMAN: At that point, we didn't know too much about it. Really, we really don't know too much about it now, (Laughs) when you get right down to it. The diagnosis was more important along the way. We moved to Vermont when she was 10 and the reason we moved was, one, I was out of a job and the other, we had the choice between New Jersey and Vermont, and Vermont was integrated greater into the school system. New Jersey was not. So we came up here. The diagnosis, etc., gets in the way sometimes and sometimes, it helps. It usually doesn't mean much.

LISA LIEBERMAN: You have other kids?

PAUL BAKEMAN: Yes, Eric. He is three years older than Jen.

LISA LIEBERMAN: Did your parenting change after you became aware that something was different?

PAUL BAKEMAN: Oh yeah. It had to. (Laughs) The major things that helped us in our early years were friends we gained while we were in Vermont and who had a child that was Jen's age. He also had autism. They were very helpful and we got some early speech therapy from a person who was down in the Albany area. I can't remember what agency she worked through, but she always had faith in Jen, and she could see the spark in there. Jen was not speaking at the time. You know, her first words were probably when she was five or maybe six. She speaks now but limitedly.

LISA LIEBERMAN: I remember Jen sat in board meetings and danced to the beat of her own drum and delighted in it…

PAUL BAKEMAN: She likes people! She likes to hang out in the back of the room and know everyone there. (Laughs)

LISA LIEBERMAN: Well, I'm just going to share a little bit about my situation because that is the most important issue here. Jordan was also diagnosed at the age of 2 1/2 with PDD-NOS. Probably for the same reason. We had just moved to Portland, Oregon from Yakima, Washington. I called the pediatrician and he said, “of course it is something that is much milder." The first time I heard the word autism, I ventured back in my mind to the psychology classes where you see a person just rocking in their own little world. Of course, I was devastated. It took me three years from the time I wanted to have a child to the time that he was actually born. I had a lot of infertility issues, I was 38 at the time. The diagnosis was a huge blow at that point in time. Of course, my view of autism has changed so much just in the spectrum of neurodiversity, I will say that. And I do want to say one thing. We are very lucky because the first person we ever saw told us two things and he couldn't have told us better things.

One of them was, this child has had optimal parenting thus far. He honored us as parents. And then the second thing he said was, find out what his strengths are and build on them. I couldn't have asked for better information or better message from that person. At that point, I had just learned that my husband had earlier stages of multiple sclerosis. He is now completely quadriplegic with MS. and has been a very different journey for me. I said to people, "I'm going to find out about this thing called autism and I will be back." I ended up specializing in disability and differences in family from that point on and that was 32 years ago.

I am so glad I discovered Autism National Committee. I had a friendship with—and some of you will figure out who that is—and she was initially on the board and she told me that it was something that fit with my philosophy and it definitely did. I became aware of the fact that I really thought I knew about autism and when I got on that board and began being around people in learning about FC, I became a neophyte and all of those people became my teachers.

My son, I have said, was my greatest sorrow initially and my greatest teacher ultimately. All my dreams for who I thought he would be died early on and yet, I had visions of us singing together, performing together. I am Jewish and I had visions of him becoming a bar mitzvah and of course, all of the other milestones--graduating from high school, going on to college, developing a career. All of those things kind of blew apart and I think for me, I did not have an open mind view of parenting, and I fortunately had some friends who were older parents and I viewed them and I learned so much about honoring the person and honoring the individual. I would say the biggest thing that happened for me, is rather than seeing behavior on the part of a child as a “won't”, I began to see it more as a “can't”.

And that he really was doing the best he could. That was quite a process for me. I had to get help. By the time Jordan was nine, we became partners. Up until that point, it was a very, very difficult transition for me. He is now 34. He moved out a year ago into an apartment with support. It is a building for people with developmental challenges who are into the arts. By the way, Jordan and I have performed many times together. He has a driver's license, he has been working now for about 10 years, part-time, grocery stores and the gym. He is contributing.

He is a very social justice minded person, a deep, deep thinker. In the end, he has been such a tremendous blessing and I to have come around as seeing autism and neurodiversity as a continuum. And my view of parenting just did a 180 in terms of what was necessary. I don't know about you guys, but I feel if I could start all over again, I could maybe parent any child because of what he has taught me. I am very grateful for that at this point.

LISA LIEBERMAN: So Paul, if you could send a message back in time to yourself at the moment you learned Jen's diagnosis, what advice would you share with your past self?

PAUL BAKEMAN: I would say just relax and do your best to help her be what she can. I think initially, I was kind of rejecting that she had that problem, etc. It would have been better to work on it earlier. Fortunately, my wife was on the case.

LISA LIEBERMAN: OK. And how about you, Sara, what would you tell your former self at the point of diagnosis?

SARA ARSHAD: I think that I would say to myself, remember that I am the mother of three, and that also my focus had been so much on my attention and anxieties that focused on Yasmin, my youngest, I regretted that my other two children may have felt less important.

I wish I could go back and tell myself, not to try to do it all. That others could help me as well. So, I did not have to push everyone away thinking that the only person who can handle Yasmin was myself. Of course, I would want to tell myself about facilitated communication. If I had known that, and Yasmin had been able to type from an early age, life would've been very different for all of us.

LISA LIEBERMAN: Have you been able to have that conversation with your other kids?

SARA ARSHAD: Yes.

LISA LIEBERMAN: It's important we recognize that we all at any given moment, are at capacity and it's easy to look back and have regrets about what we could do and couldn't do. And to give yourself grace about how we did the best we could in that moment in time and couldn't have done it any other way. You had the shock of a diagnosis and you did not expect it. Thank you for opening that up to us, because I'm sure all of us have had really raw, vulnerable spots that we carry inside.

I appreciate that you shared that with us. Thank you. OK, I am going back to Sharon. What would you tell your former self?

SHARON KOEPPEL-MEDINA: I think one of the most important things, this didn't necessarily come from me, it came from Rosemary Crossley, is to always presume competence. Just because a person doesn't have verbal speech, you need to presume they are competent. And that alone, can make the difference in the world. I always tried to focus on the positive. Instead of things that were maybe driving me crazy, like he picked up a new habit of flipping or flapping (Laughs). Sure enough, that passed and some other behavior came on board. It was kind of like, just reading the room all the time.

Be open to all therapies. I know when auditory integration training came around, a lot of people who had children with autism had them participate in that. Yes, it did make a difference. He was very sensitive to loud noises and certain frequencies.

It really helped him calm himself. Just each and every day, I helped him to realize his potential. The sad thing, I guess in the last few years, besides COVID, was that in March 2020, when COVID first hit, Chris lost all of his staff. He lost his case manager, his primary support person, his employment support people. I was working part-time, and luckily I had already retired from 38 years of teaching but was working part-time. And I had quit basically because he needs 24/7 supervision.

It's hard for him to recognize what might be dangerous. Sometimes he's let people just walk into our house (Laughs). I don't feel comfortable with him around traffic, if he's walking downtown or in an unfamiliar place.

LISA LIEBERMAN: I heard that you presumed confidence. We used to hear about it endlessly from Anne Donnellan in that area. And it was life-changing for me as a parent, and focusing on the positive. I love the quote, "budgets have deficits, people have gifts." Not looking at what was wrong or broken but focusing on the positive. And being open to all therapies. Marie, what would you tell your former self?

MARIE GIONGO: I think basically it would be just as for any parent, if I was telling someone else, it is that, it's a blessing. It's a blessing and enjoy the ride because “the days are long but the years are short.” It's so true. To trust your gut, as parents, you have to trust your gut. Don't be afraid to advocate. I try not to have regrets because, you are where you are supposed to be. But there were times where I thought I wished I had pushed harder or done this or that. Like you said earlier, we do the best with what we know. When you know better you do better.

I think that's it. What Sara said about siblings, I get that because having two others you always wondered, you are being pulled in different directions. But your kids get it. If you're doing it for one, I'm sure you were also doing it for the others. The others know and they understand and it's one of those things. Being forgiven, giving yourself space, you are allowed to be human. Enjoy the ride.

LISA LIEBERMAN: Now we are going to Dennis. What would you tell your former self at point of diagnosis?

DENNIS MASHUE: The presumption of competence. It's so important and difficult when all of our medical and educational professionals, are advising us otherwise. I think my message back to myself would be, value your position in your child's life. Because really, nobody knows that child better than you do. When you get into a room with a medical professional or educational professional, and you reach the point where you think, "I think I am the expert in the room here." Because what they are saying does not sit well in your gut, and you think "that does not apply to my child". That would be my biggest thing. Value your own value, as an advocate for your child.

LISA LIEBERMAN: That's really important. OK, and Danielle.

DANIELLE VAUTHY: Just everything all the parents have said is resonating. I think, one of the things that I would like to go back to my former self and say is that this is a long game. Matteo is only diagnosed for the past two years. In the two years I've seen much in his development. I think I would say to myself, a lot of the things you are worried about, he will grow out of. He will develop out of.

Knowing that I don't have as much worry, telling myself, you don't have as much control as you think (Laughs). Relax! (Laughs) And the other thing, that Dennis just said which really hits home for me is to trust your gut and your own parenting instincts.

At the beginning of Matteo's diagnosis, we were struggling with some medical decisions about medication. I knew maybe it would help him. But the people around me, there was a lot of stigma around it. Now go back and say, trust your gut. You know him best. Enjoy the ride! (Laughs)

LISA LIEBERMAN: That's wonderful, I will throw in my two cents. I jotted a few things down. I would tell myself to appreciate more who he is, was as a person. And not have the big shroud of autism over his head and not necessarily always viewing him through that template. Of autism. My son really balks at that and he will say -- he will hear me say to someone that "my son has autism". He does like me to call him autistic. It's controversial across the field. I will hear him sigh. He doesn't have that sense of chauvinism or positive identity as having a tribe. I tried to talk to him as how he has many tribes who are into photography and a tribe of people into music and who are Jewish, and who are neurodiverse.

He doesn't like neurodiverse because the opposite, the opposite is neurotypical and he will go off on what is typical. I know at one point they wanted him to consider being on the board and it would've been a disaster because he would've been expounding his philosophy the entire time not being able to get past that.

When I began to see him as my teacher, and as a co-collaborator, everything changed. We developed a partnership and that is what I would've told myself maybe earlier on. I shared with you guys that it was just a really rough ride for me. Not only was I dealing with my husband's diagnosis, I was raising two-step kids that lived with us. They were leaving the home. And then, this much wanted child, had to deal with the change in dreams.

Maybe another message might've been, to be open to what's possible. Rather than seeing it as the shroud that will be over our head. Of course I got there. I did that in my own time just like our kids do it in their own time. I remember one time I went for a walk with him, up the street, and people always said don't talk about your child in front of him, about his label or whatever, and I was talking to a neighbor. The neighbor asked him a question. He was probably about six or seven at that point. He didn't answer. And I felt nervous. And so I spoke up and said, "Jordan is a very smart person it just takes him a little while to process what he is hearing because he has autism. Before he gives you an answer to the question." As we walked away, they took it really well. As I walked away I said to myself "damn I did it!" I said to Jordan, "Honey, do you know what it means when your mom says you have autism?" He thought about in a minute, and the inflection will go up at the end of the statement, he would say, "it means I have to relax a lot?" And I thought, you got one of the really important things. He had been taught progressive relaxation in school.

And he needed that and did a lot of sensory integration. That is when I realized that we can be partners and collaborate. Like I said to Sara, I can't go back and change whatever time it took me to get there. Because it was really me that had to go through the learning curve, not him. He was just being who he was.

All right. So, the last formal question we have here is, what are some things other people said or did for you or your child, that you are especially grateful for? I will come back to you, Danielle, on that one.

DANIELLE VAUTHY: Well, Matteo was diagnosed in the middle of the pandemic. It was probably the only good thing that came out of the pandemic, was that remote learning was just a catastrophe. It was just for him. The vice principal of the school, and his teacher, really became collaborators with me, and really pushed his entire support system to get a formal diagnosis. So that was one thing that was extremely helpful.

The other thing, uniquely, was when Matteo was about 11, we had become a new family. We blended families with my partner. And my partner, had a very unique view. She'd only lived with Matteo for a year. She had a perspective on him and she saw things needed that I just had not, that I had just accepted as OK, for the way that my family was running. A lot of it has to do with no structure. She really helped me see, in putting structure in our home, it is really phenomenal for not only Matteo, but also the other kids.

Having a mom that is an autism specialist was extremely helpful, and unique to have that as well. She got me great resources. We live across the country from each other, so she found somebody that gave him a diagnosis. The diagnosis that we got was so line by line, what services he needed and who in the area could help me with those and that was so helpful for me because when you get the diagnosis, it is so overwhelming that this kind of gave me a map to try everything out. Having that, I still refer back to it now two years later, and I am sure I will refer back to it 10 years later, all the things that she felt would help Matteo.

You know, the services that he is getting now, he has his OT and he has services that are outside of school, OT in and out of school. That has been just having an entire system of people working to help him, accepting the help (Laughs) so, I've gotten quite a lot of help and from all different places.

We are at a really good spot. It is because of all of the people around me that have chipped in to help, and also Matteo! You said, earlier, Lisa, that collaborating and having them become your collaborator and he is at an age now where he can be. That has been such game changer because a lot of that is a buy in. If he doesn't buy into it, if he doesn't buy into a certain therapy, then he doesn't! If he doesn't buy him into a certain system that we have to help him, then that is not going to work.

Having your child be a collaborator is very key. I have only really experienced that for the last year. He is old enough. I am just really grateful for all of the support that I have gotten. Accept it! If people are offering, except the support.

LISA LIEBERMAN: I have a very outdated website, because I really am in the sunset of my career but the last thing I put on my website, I want to share with you guys, is the last article that I published that is called “The Gift of Interdependence.” It has never been my goal for my son to be independent. It has been my goal for him to have the experience of interdependence because we are all interdependent. And so, this issue of asking for help, I am not trying to self promote. I just want this to be available to you guys. My website is disabilitinthefamily.com. It has articles to upload and this article is at the top. I'm sure it is going to resonate for most of you if you're so inclined. It is disabilityinthefamily. Of course, my son groans every time he hears me say that too.

Dennis, what are some things that people did for you or your child that were helpful, that you are grateful for?

DENNIS MASHUE: I will break this into two things because, like I mentioned, I came from a position of extreme ignorance with regard to disability, autism, neurodiversity, all of that. Early on, when I say early on, my son is already probably 14. I was in my late 40s, maybe 50 years old. I encountered a woman from South Africa, named Tania Melnyczuk. She helped me understand that I was still stuck in the vaccination component as the creator of Autism. She helped me understand that this is a genetic thing and there is a lot more to it than what I had learned. That was big for me from an overall perspective on autism, I guess, and it just changed my perspective, totally.

The other was, a woman named Eustacia Cutler, whom some of you know as Temple Grandin’s mother. She came and did a presentation in our little town in Michigan for the school district. She basically set the entire district’s philosophy on its ear, about the ableist perspective. She asked a couple of questions and then during the Q&A, I asked a couple of questions. She pointed down at me and she said, "You sir are a good father." And she asked me to sit down with her for a cup of coffee after her presentation, and we just talked a lot about things, particularly the value of a father in the lives of the kids, because, you know, fathers, if you are not able to fix some things, tend to lose interest and go another way. That really hit home with me.

At that point, I went on a quest of finding other self advocates, and they taught me the value of being, allowing my son to be his authentic self. Me, to be my authentic self. Stop trying to fit the mold that society has created for what we should aspire to.

Our friend, Maxfield, was one of those people and has been a tremendous influence on us. I will stop there before the tears start.

LISA LIEBERMAN: The tears are wonderful and I appreciate you sharing, again, to that vulnerable level, because it opens it up for other people. I think all of us, need to hear in one way or another, that we are doing some things right. There's just a couple of things I want to say. One is one of my favorite quotes, and it came from a teacher named (unknown name) and the quote is, "Pity is watching people from afar with fear, and compassion is with a loving, open heart."

I don't know about you guys? But I smell pity from a mile away. It is very isolating. It is very upsetting. I think, what I have decided is that pity is really about people kind of keeping at a distance from a thing that they perceive as their worst nightmare. They don't understand the gifts that have come into our life.

I very readily use the word smell, I don't know why, but I smell pity and I smell compassion. I am being, at this point in my old age, I am being much more mindful of the people that I want to surround myself with and the people that I want to welcome into Jordan's life as friends of mine as well.

So, the other thing I want to say is that I understand that some of our attendees who are not panelists have questions and please feel free to post those questions in the Q&A.

Let's ask Marie that question, what are you grateful for, for either your child or for you?

MARIE GIONGO: I'm grateful for being here today and for everyone. The key word that I've been coming to today is vulnerability. I think that is how we get to the truth and we help each other along. I want to say thank you for everyone for that. I really do appreciate it. I think for me it is my husband because whenever we needed each other, we had each other's back. I knew, going into this, that I had no better partner to really have our son's back. Who got it. We would do anything for any of our kids. That is number one. All three of my children.

As for Michael's siblings, especially, they treated him like Michael. He was their brother and you know, remember they are both younger than he is. I remember my son would say come up with “Michael look at me." He wouldn't put up with it! He treated him like Michael. He saw him as Michael and that was that.

Their friends, as an extension, are seeing Michael as Michael and just accepted and included. There is a big difference between pity, that’s thinking we are doing a favor, versus we are accepting you. It was the people who accepted us along the way, who really just made life better that way. And for all of us at all different levels.

There are other parents who have had it, or the specialists that I could tell that they were going to do their best for my son. And then, I will say, now too, as an adult, I wondered as he going out into the world, How will the world receive him? There are people out there who would take advantage.

I would say that for his career, he has come across people who are just wonderful. I know, when my son goes to work, I have nothing to worry about. I know the people there love and support him and they have his back. It is really a beautiful blessing.

I realize that there are angels amongst us who really do care. We are always in this journey together and that is the way that I look at life. We should be helping each other along, not trying to take each other down. I’ve really seen that in our life.

LISA LIEBERMAN: That is wonderful.

MARIE GIONGO: Thank you.

LISA LIEBERMAN: Sharon? What are you grateful for? Who helped you, who helped your child?

SHARON KOEPPEL-MEDINA: There have been so, so many people. Both through school and different activities that we were involved in. I think that they accepted Kris, they appreciated Kris, they celebrated Kris. The peers that he had in his classroom were mostly supportive based on the teacher's actions. In other words, Kris wasn't singled out in any way. Peers were encouraged to approach him, asked to play with him, be part of his social circle, call him on the telephone, things like that.

And then, just the many teachers, therapists, and pure educators who helped him in his classes. Through his community supports, he had a lot of wonderful people that exposed him to things in the community. I just can't wait until things change, to where leaders value that people that we need to support our sons and daughters need to be paid more. They are not being attracted to positions and are leaving our vulnerable population in the hands of their parents. We all know that one of these days, we are not going to be there.

That's why I'm fighting so hard to get more housing things going in Vermont. Right now, we only have one system and that's a shared living provider. It doesn't really work with the majority of people.

LISA LIEBERMAN: Thank you, Sharon. OK, Sara, what are you grateful for you or your daughter?

SARA ARSHAD: I'm grateful that I learned when Yasmin was in elementary school not to be afraid of her seizures, and she wasn't as fragile as I thought she was, and that was a big step for me. It's difficult when you have a nonspeaking--nonverbally speaking--adult child, to get any kind of socialization with people who are neurotypical, unless you pay them. I'm extremely grateful that Yasmin has had a truly deep friendship, that she met Olivia, when Olivia and she were babies. Olivia accepted her for who she was and they were best friends. And her passing, three years ago, has been devastating for Yasmin and have left us all bereft. That degree of friendship is rare for anyone.

I am also extremely grateful to Lisa for introducing us to this facilitated communication. And, case in point, while panelists have been speaking, Yasmin typed this message for me. She wrote, "Mom you're hoping to be perfect. Get over it."

(Laughter)

SARA ARSHAD: She wrote, "be proud of what an awesome mom you are and I am grateful for everything you have done for me."

LISA LIEBERMAN: Thank you, Yasmin.

SARA ARSHAD: I also want to say it helps to have such a close knit loving family. That helps.

LISA LIEBERMAN: Paul, last but not least.

PAUL BAKEMAN: There've been many people throughout our life, that have helped a lot. It's hard to pick one out, or two or three. But one of them is when we first came to Vermont, Jen was 10 years old. And there was a teacher in the elementary school. Joe (unknown name) was her name. She said, "We can do that and put her in school." She had never been in a public school before, at 10 years. So, the first three years went well, the other kids accepted her completely. There was no problem there. As time went on, the problems developed more with the professionals than the kids.

The kids were always supportive of her. They'd watch out for her on the bus, etc. Come down and wait for her. So, you have to appreciate kids sometimes are smarter than we are. And my son was very helpful as well. Unfortunately, we burdened him with things that wouldn't normally be expected of a three-year-old, and watching his three-year younger sister. But he did that and we probably neglected him some as well. Because of -- Jen.

More recently we found a psychologist that is typing with Jen and she has resisted facilitated communications ever since it started. People worked with her but she never really, how do I say this? She didn't seem to want to communicate that way. She just kind of resisted. We have a session with Mike every week now, for an hour and she types back and forth and passes an iPad back and forth, but she does not like the contact stuff. That did not work with her at all.

There's a lot of people, throughout the years, that have been very supportive. And some that have not. But we appreciate the ones that have.

LISA LIEBERMAN: I am so glad that the theme has been here, of letting people in to help. Hillary Clinton, got it right when she said it takes a village. In my situation, my only sibling was paranoid schizophrenic and took his own life in his thirties. Both of my parents are gone, and I did not have a lot of extended family. So, for me, and as my husband's disability worsened, it was all on me. And if I hadn't been comfortable with allowing or inviting people into our circle… Jordan had one on one support providers up until the time he was in eighth grade.

We had part-time people. I had to work. We had more and more caregivers come in for my husband. I couldn't have made it without their help. I learned so much from them. My son got the benefit of different people's perspectives and their delight. The people I am most grateful for are the people who get who he is and value who he is as a person. I'm just gonna brag a little bit and say, as I said before, he's an emotionally intelligent person. I never see him walk away from a conversation where people are not smiling. He's quirky and so extroverted. He will not leave a party without making sure you say goodbye to every single person. He's much more so than I am.

I get a lot of brownie points for being Jordan's mom because of who he is. I'm grateful to him and he had a ton of therapies. Speech, vision, occupational, craniosacral therapies. By the way he had a major seizure at the age of three out of the blue. At that point in time, the medications made him unteachable, unreachable, climbing the walls. At that point in our life, we went Naturopathic. I'm very grateful to all those people. I was told by an MD who began to specialize in autism, that it was a result of working with Jordan, and he had Jordan to thank for that. It's time to take some questions.

Lisa, will you read a question?

LISA KELLER: The first one is from Nicholas Moore.(Reads) “Dear moms and dads, I'm so sorry, really do understand you did the best you could. As did I, Nicholas, who by the way is autistic or has autism. Please know I supported you and everything you tried and love you unconditionally. Allow me to fail, and yourself as well, and trust God to do the rest. Love always, your son and daughter.”

There is one from Liz Goldenberg. (Reads) “I've a question for Sharon, and anyone else involved in parent groups. Working to develop housing for their adult children, where are you in the process? Can you share contact information so we can connect? I'm working with some parents in central New York and making good progress. I would love to know what is happening in other parts of the country. If there is not enough time to respond now, please contact me at a later time. Thank you to all of you for your vulnerability and all you are doing.”

We will probably need to get Liz and Sharon hooked up together.

SHARON KOEPPEL-MEDINA: I did go on, and read it, and responded and gave you my email and the name of our group.

LISA LIEBERMAN: I would like to add to that my son is living in a nonprofit building. He has to pay market rent for it, but it's called Belong Art Community. It's BelongArtCommunity.org. I will say the social worker in me wants more involvement in the community, but it's so much better, than what some of the options are out there. I'm in Portland, Oregon. Because some of the things my clients, adult kids, some places they are living… it's very upsetting to me.

The attitude of the providers and the parents are not able to let go of their hypervigilance about how their child is doing. But Belong Art Community is based on or for people with development challenges that are interested in the art cinema music studio, art studio, fitness room, music jams once a week, community potluck. Trying to build community within the building.

It's a very unique place. If I could do one thing I would get them to share their model. I invite all of you to please contact them and let them know that you have heard about the program. So, it is belongartcommunity.org. Please reach out to them and I'm trying to be surreptitious here about getting them to be more responsive to sharing their model because it's a very unique model. OK. If any of them listen to this webinar, (Laughs), I may get my hand slapped, but that's OK.

LISA KELLER: (Laughs) OK so then we have a question from Margaret Heath and I've already answered it. But I don't know if this applies, everyone wants to hear. (Reads) “I’m Margaret Heath and was Guardian for Eve for a while in the nineties and early 2000's, who was one of the pioneers of FC before it was a technique. I know she would love hearing all of you and hearing about her peers and their lives. So my question is, whether there will be a recording that I share with her current helpers? She doesn't get to FC much now, but one helpers is keeping this alive for her. This would be so meaningful to her.

I said to Margaret that I used to work with Eve, when I was at (unknown name) and I'm in a private practice now. Margaret can email me, at my email which is lisakeller422@gmail.com.

I want to say that this is being recorded and we are going to put this one up as well as the one that we had in March. We are sending it to all of the registrants. Look for that in your email. [Afternote: Sadly, the recording was not captured after all, which we regret immensely. We are glad that we can share this transcript in its place.]

Also, Dennis Mashue said, Liz, check out We Build foundation. They have built a community in Oregon and are currently advising a group and Weld County, North Carolina, to develop their contract. My contact email is drmashue@gmail.com.

LISA LIEBERMAN: I am very familiar with We Build. I have a couple of clients whose kids are living there and it is another unique model. They have more of a concept of being neighbors and some of the residents are owners of the units in some of our rentals. The residents share in the profit from the rent. And I think that Ann, I am blocking her last name right now but Ann has actually identified somebody to to replace her when she moves on. Which is wonderful. Somebody is taking about the longevity in terms of the housing.

I saw that there was a question about discipline. How do you discipline a kid? How about we read that?

LISA KELLER: This is from Tabitha Davis: "Thank you for the webinar full stop. How do you approach gentle disciplining your artistic kiddos? I have a four-year-old little boy, partially verbal, who we want to set up for success with the right habits and ways to interact with others. Sometimes, this means you need to tell them no or deny them something, if it is for their safety, etc., as an example, and then the tantrums began. I will be honest, most times I feel overwhelmed when the tantrums happen, because they are increasing and liked and I don't want to reinforce these behaviors. But I also don't want to indirectly cause harm by doing the wrong thing either. Any help on the matter would be greatly appreciated."

So, Lisa? Feel free, if anybody wants to answer this, please raise your hand.

LISA LIEBERMAN: The things that I was told, first of all, always assume the behavior is in the direction of autism before you see it as intentional. You know, you guys have all heard, "Behavior is communication." The other thing, as many of you probably know, the root of the word of discipline, is disciple, which means the teacher or helper.

Discipline is teaching them or helping them to learn ways of expressing themselves that are maybe more effective. Of course, is harder with a four-year-old, but you are also dealing with somebody who is developmentally much younger than four and so, it is helpful think, in that case, to think of them as maybe like a two-year-old. I remember, with Jordan, I would give him choices. He finally became smart enough that he could say no to all of them but for a while it worked.

And if I asked, you want to do this or this? He felt like he was more in control. I think it is about giving our kids as much of a sense of control as we can with, the parameters of safety and reasonableness in terms of the context that we are in. Maybe somebody else wants to respond to that too. Marie, do you have your hand up?

MARIE GIONGO: It was from earlier, but I wrote down a couple of things. I think first breathe. Breath is your friend. When you are in that situation, you're not the first parent and you're not going to be the last parent, so even if it is somewhere when it is not an optimal situation, it is OK. It is a child and he or she is trying to express something.

They are frustrated, they are confused, angry, tired. Whatever it might be. I would even say to my son, "I'm sorry I don't know why." Or that way. I agree with the frustration. Giving him or her options. I also think to keep it simple. Especially if he is not safe, I would say, if it is something like, we don't do that, you could get hurt. You know, we could do A or B, the options, the choices.

If it is something really specific you’re concerned about, ask the support people around you because they might be able to provide you with some options. I think some parents and public, I see them and I just you know what? It is OK. We have all been there, we have all done that. You are not doing anything wrong. It is your child trying to express something.

LISA KELLER: I just want to remind people that it is 10 minutes until one so we only have time for one more question. Unless somebody wants to ? does anybody want to respond to Cabot this question? -- Tabitha's question? I do want to say, that in autism, it is important to note that children typically do not have temper tantrums to gain something from somebody.

It is not manipulative kind of thing. With autism, it is a combination of sensory overload. And when it gets to a certain level, it all spills over. They have meltdowns. It is not that they are trying to manipulate their parents or teachers or whoever.

So, I just wanted to make that point. We have one more question that I'm going to take. It is from (unknown name). Hi (unknown name), I haven't seen you in a while. "When I retired as a special ed teacher, I eventually found a niche working with adults who use facilitated communication, adults who are nonspeaking. I continue to be concerned about the need for better services for adults. It seems, the staff who support these individuals and their homes or work or day programs, have far too little in the way of training. And too many have the idea that their role is to take care of the young people rather than help them learn to do things for themselves." Well put. "I greatly appreciate all of the information that you are providing about adult services."

I want to also say that we can put the resources into our next newsletter, “The Communication”. Submit them to Judy at judybailey@aol.com. If you are not already members of AutCom, it is very inexpensive and it really helps us put these kinds of webinars and conferences and things like that on.

You can go to Autcom.org and it is $10 a year if you are artistic. You'll see that if you go to AutCom.org and you say join our membership, it is all there and you can send your check.

As I said, we are going to put a recording of this webinar [if possible] and send it to anybody who registered. We’ll put a link in the newsletter.

LISA KELLER: Dennis asked where we can mail the application and membership application and fees. I will type it in. [Check the website for the address on the membership form.]

LISA LIEBERMAN: Lisa, it be OK if I just give a little spiel here for second?

LISA KELLER: Go ahead.

LISA LIEBERMAN: I used to do a lot of national speaking and I had a talk that I always called “Emotional Journey for Parents: Tools for the Emotional Journey.” I just wanted to summarize the tool and the most important one, and they are not actually sequential. Don't read them as linear. First, is to allow all feelings and that there are no feelings that we have that are wrong. It is only actions that we need to control but we can't control how we feel.

If we can acknowledge all of the feelings, we can open to new dreams. I’m doing a whole day workshop in about two minutes here. The third, where people usually start, is gathering information and resources. We get on this steep learning curve and jump in and try to learn everything we can.

The fourth is, becoming an Ambassador about autism to the world. You know, and when your child is little and also becoming an interpreter of the world for your child when they are young.

The fifth is developing connection and support. The sixth is balancing personhood and parenthood. That we still need to be able to pull over into safe harbor and do things that feed our soul and it may mean that we need people to help us figure out how to do that. That takes such effort, it is so hard to do that when you're in the throes of so many things.

I have given you my website earlier. It is disabilityinthefamily.com.

LISA KELLER: It is time. I want to thank everybody. What a panel. This was awesome. Let's applaud.

This was great. I don't think I could have asked for better panelists and a better moderator. Lisa, you are amazing. Please follow us on Facebook. We are under the AutCom Facebook group.

I guess the only thing left is to say thank you and please join AutCom.

LISA LIEBERMAN: There is a lifetime membership. If people are so inclined, or want to support the organization.

I just want to tell you really quick, I put another website into the Q and A for a very gifted person in Portland who is doing things on Zoom and she has a free peer support group. She did amazing training. Her name is Barbara Avila of SynergyAutismServices.com. She is helping me to separate from my son in terms of letting him handle things.

Live captioning by Ai-Media

Note: The transcript has had minor editing for continuity and readability.