



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 043

Autism Legal Rights & Transition to Adulthood: Interview with Autism Attorney Gary Mayerson

Hosted by: Dr. Mary Barbera

Mary Barbera: You're listening to the Turn Autism Around podcast, episode number 43. In today's episode, I am interviewing Gary Mayerson, who is an attorney and we're going to get to introducing him in just a second. Before I do that, I'd like to give a listener shout out to Merissa who left me a five star rating and review on Apple podcast. She said, "This is a show that is much needed for anyone dealing with autism in their lives. Mary knows her stuff and has so much help and hope." So thank you, Merissa, it is my pleasure to offer help and hope and that is really my goal here for both parents and professionals.

Mary Barbera: So if you have listened to the podcast before, I would love it if you could go on Apple podcasts or wherever you're listening and leave me a great rating and review for my show, and that will help me spread the word to others who might be interested. So now I would like to introduce our guests for today.

Mary Barbera: Gary Mayerson is an attorney. And in the year 2000 Gary founded Mayerson and Associates as the first law firm in the nation dedicated to the representation of individuals with autism. To date, Gary and his staff have assisted more than 1200 families in 35 States and are responsible for more than 150 federal court decisions, including the first autism case to reach the US Supreme court. Gary is the author of *How to Compromise with Your School District Without Compromising Your Child* written in 2005, and Gary is finishing a second book *Autism's Declaration of Independence*. So in this interview we are talking all about autism and the law and Gary's books and his experiences, and he's a wealth of information. So let's get to this interview with Gary Mayerson.

Welcome to the Turnout Autism Around podcast for both parents and professionals in the autism world who want to turn things around, be less stressed, and lead happier lives. And now your host, autism mom, behavior analyst, and bestselling author, Dr. Mary Barbera.

Mary Barbera: Okay, so now I'd like to introduce Gary Mayerson. Thanks so much for joining us today, Gary.

Gary Mayerson: My pleasure being here. Thank you for inviting me.

Mary Barbera: Great. So, I just introduced you formally and we've never met before in person. So this is the first kind of virtual meeting we're having. I'm just wondering if you can, like I usually start my interviews with describe your fall into the autism world and how you got involved...

Gary Mayerson: Fall into the world is appropriate language to use. Because I really was the accidental tourist. I was busy minding my own business. I was a partner in a sizable law firm in Manhattan representing wonderful people like Donald Trump and others.... don't ask me about that.

Mary Barbera: Yeah, we're going to leave that part of the question off the table.

Gary Mayerson: But, you know, we had a family member diagnosed with autism and that changed our lives overnight. And as part of that change, you know, my wife and I found that we had resources and it was difficult for us to even find appropriate services and effective services. And I started thinking over time, Hey, you know, what about families that don't have resources? And you know how difficult it must be for them. This is in the 1990s when all this is happening. And you know, there were a lot of different theories and so much was up in the air. And I said to myself, why doesn't somebody start a law firm that's dedicated only to people with autism? I mean the where that's the focus of the practice? And that's what I did in 2000 and it's the best decision I ever made.

Mary Barbera: Wow. So that was 2000 so we're almost two decades after starting your law firm, dedicated almost exclusively to children and adults with autism. So how many cases have you represented and what are the, you know, general reasons why people would utilize your services?

Gary Mayerson: Well, I mean, I look back over time. I mean, it's hard to get an exact number, but we're talking about clearly over 1200 families since 1997, which is when I first started doing this even before I started my own firm. So that's over 1200 families in approximately 35 States. I mean you just name a state. We probably have done it. And we also have consulted internationally to military families or people that are ex-patriots who are coming back to the United States. So it's a fairly broad practice with a lot of, you know, consultation and a lot of litigation. The kind of cases that we, I would say our bread and butter, are tuition reimbursement cases, particularly in the New York City area where there are a number of

autism based schools that are offered one-to-one applied behavior analysis or other effective teaching strategies that may not be available in the public school system.

Gary Mayerson: So we do a lot of tuition reimbursement cases. We sometimes work on cases to enforce IEP mandates so that the child will get the services that are mandated on the IEP. We've done bullying cases; we've actually had a sexual assault case in the mix. Employment discrimination cases for people who have, you know, gone over into adulthood and have this same kind of bullying that you may have in a public school context spills over into the employment context sometimes. And oh my God, you know, accommodations issues involving students that want to go onto college and what type of accommodations they'll get for extra testing time, or a quiet place to take the test and so forth. There's no end to the kind of cases that we've done. I mean, just every day when we pick up the phone, we never know what's coming. It's almost like the box of chocolates from Forrest Gump: You never know what you're gonna get.

Mary Barbera: You never know. Wow. So I know in the introduction I said that you were involved with the first autism case to reach the US Supreme court. Can you tell us what that was about and how you were involved?

Gary Mayerson: Sure. Well, that was the deal case, which was in based in Chattanooga, Tennessee. And it was very symptomatic of what a lot of school districts were doing in those days, particularly with respect to applied behavior analysis requests. The family had tried out applied behavior analysis and it worked for their child, and they went to the school district to ask for some help to try to put together some funding or something so that their child could get applied behavior analysis from the school district. The problem was that the school district wouldn't even discuss the topic. I'm not saying that they rejected applied behavior analysis. So I'm saying they said to the family: not for discussion. We're not going to talk about ABA. It's a methodology. We don't have to discuss it. So everywhere the family turned, whether it was an IEP meeting, trying to meet at the administrative offices, writing letters, whatever they tried, they were rebuffed at every turn. And the school district just simply refuse to discuss applied behavior analysis.

Mary Barbera: And what year was this around?

Gary Mayerson: This is approximately from 1998 to 2004, in that period with all the appeals. And I'll tell you about that.

Mary Barbera: So it was well after the Catherine Maurice's books, which really started the whole call for ABA and the requests for ABA. So 1993 was Catherine Maurice's first book, Let Me Hear Your Voice. And then 1996 was the, you know, the, the behavioral intervention book and that really... I'm sure you would agree that that really stimulated a lot of court cases.

Gary Mayerson: Oh, absolutely. You know before his death I met numerous times with the Ole Ivar Lovaas. I had him and his wife in my own home and they were just wonderful people. And I met Catherine Maurice a couple of times and, you know, it was a watershed moment when that book came out. In any event, the school district in Tennessee refused to discuss ABA. We went to a hearing; it was a 29 day trial. Can you believe it? A 29 day trial. And if it was up to me, it would have been over in two or three days. But the school district had a lot of witnesses to put on and they were... My sense was they were trying to drag it out so to bleed the family dry.

Mary Barbera: And it was 29 days in a row?

Gary Mayerson: No.

Mary Barbera: Yeah. Cause when I went to due process it was 10 days, but it was over the course of like over a year.

Gary Mayerson: No, this was over the course of several months. And I would have to fly back to first Atlanta, take another plane to Chattanooga. Worst part of it all, I don't want to say the name of the hotel that I was staying at because I don't want to ruin their business, but it was the kind of hotel where the person at the front desk was not even wearing a shirt when they check you in.

Gary Mayerson: But putting that aside, it was a great case though because it really established a very important principle, which is that when parents ask for some consideration for something, that you have to at least give them the courtesy and respect of a meaningful discussion. Okay. So the hearing officer found that Chattanooga's school system had deprived this student by not discussing ABA, by refusing to discuss the topic.

Gary Mayerson: And of course they took an appeal to federal court and this went on and on. We went to the sixth circuit court of appeals where the six circuit ruled them just as the original hearing officer did; that they had deprived this child and this family procedurally by not discussing it. And they used a word called predetermination. Now when the school district predetermines the placement and program without a meaningful

discussion, that is a classic violation under idea that will provoke a tuition reimbursement situation.

Gary Mayerson: Now, here's the irony for the school district. This is just too awful. It's a perfect case of what a school district should not do. The school district wound up spending over \$3 million to defend this case. The entire cost of the student's ABA program is approximately 60 to \$65,000 a year. They could have bought peace for that amount. So instead they spent over \$3 million to then lose at the end of all this. And it's a big case in the predetermination claim world.

Gary Mayerson: But what it also did was that it showed school districts, this can happen to you and why it might be a better idea to talk to families about whether it's ABA or whatever it is, to have a meaningful discussion to do what's right for the trial as opposed to always getting into this battle. You know, there's constant us versus them mentality, which is just not helpful to any student or their family. And this was right around the time that the country was turning in favor of public school systems adopting applied behavior analysis, or opening up ABA programs within the public school system. And I think that was a big, big event that when this happened. And as you pointed out, it was the first case that to ever reach the US... First autism case to reach the US Supreme court and the Supreme Court refused to hear Appleton County Tennessee's appeal. So that left the court of appeals decision in place, which had ruled for the family.

Mary Barbera: And then in that situation, the school district then also has to pay all the legal fees of the parent.

Gary Mayerson: Well, I wish they had to pay all the fees. They didn't have to pay all the fees, but they did have to pay quite a bit. And you know, a sizable sum, not \$3 million, not even \$1 million, but something that made it financially worthwhile to have. I've done the case and you know, even without the money, that case was such an important case to be done no matter, even if there was no recovery whatsoever, it was an incredibly important case for the country.

Mary Barbera: Yeah. And I often tell parents that, you know, you would, you attend an IEP meeting and there may be, you know, five or 10 people from the school district and you are by yourself or without one other person. And you may feel like you only get one 10th of the discussion, but you are really an important part of any meeting about your child. And it's important to know that you also have the legal right to bring up things, bring up concerns, and legally you have a right to represent your child and to be a big part of the IEP meeting, not just a 10th.

Gary Mayerson: Right, right. I mean, parents forget, I think it's easy to forget when you're one person in the room at a 10 or sometimes even 20 or more people in the room. It's very intimidating, but you have an equal voice. And you should make yourself known when you're, when you're at that meeting. Absolutely.

Mary Barbera: So the way I first, I think I saw you speak once at maybe at the ASAP conference, or maybe I met you there and I mean, we're talking probably in 2000 or something really early on, but you published your first book called *How to Compromise with Your School District Without Compromising Your Child* and I became really familiar with your work through that book initially. So what year was that published and what is the gist of it?

Gary Mayerson: Yeah, that was 2005. And essentially what I wanted to provide parents with is a field guide, but how to go about the IEP process, how to go about confronting your school district if there was a disagreement between the family and the school district, the idea of getting quality assessments so that the argument would not be about this is what parents want, this is what the school districts wants. But rather if they change that dynamic to this is what a professional is recommending. And by changing the dynamic, it shifted the battleground to more of a clinical kind of examination, which made it easier for parents to get services. And if a parent could not afford to get an evaluation, a private evaluation, how they could get one from the school district at school district expense through and through the independent examination evaluation process.

Gary Mayerson: So... I wanted to sensitize parents to the kinds of conflicts that could come up in the IEP context. And that was... the book... it made the rounds and I think that it was very helpful to just point out these various weight points in the process to families who were just, you know, really had no idea how the process worked. I mean it's one thing to read the idea statute and even as a lawyer, they don't teach you this stuff in law school; it's just not a part of the curriculum. So you have to learn it as you go. I thought the book was important to be able to translate all of that gobbledygook into something that the parents could readily understand and then use effectively in a practical way at the IEP meeting, or if thereafter if there was a dispute or a mediation

Mary Barbera: And I read the book actually in between my first due process case when Lucas was three, and my second due process case when he was nine. And I still, even though that your book is about 15 years old now, you know considering you wrote it probably the year before that it was published, but it still is really solid. I mean there's not... Yes we have, you know, no

child left behind and we have some additional protections and more court cases that have cited either way, but I think even your 2005 book is still a very good book to read in terms of making sure you are documenting after an IEP meeting. Oh, we're going to give him one-to-one support on the playground so he doesn't elope and go into the highway. Then I'm going to put that in writing then as a parent to say, Hey, thanks for meeting with me; you agreed that you would have Johnny with the one-to-one within arms distance, or whatever you discussed to kind of solidify the plan. And then that way it's in writing and just kind of legally defend yourself along the way so that you don't end up in due process.

Mary Barbera: Because I did an episode last week that hopefully if you haven't listened to that, if you're listening, I did an episode, a solo show in preparation for Gary's interview describing my due process journey and my legal dispute journey and really my message is avoid it. Because people don't, I don't have time. You have to really be, I mean a multimillionaire with a lot of extra time to be wanting to dive into cases that are difficult, lengthy. I mean it does wear you down. You talked about the one school district trying to wear down the parents, and it's like it wears down both sides, not just the parents but the school districts. Because school districts are made up of people and they are well meaning people.

Mary Barbera: And many of you listening are well-meaning professionals who want to do a great job. The last thing you want is to know that you're thrown into due process. And I think it's really disturbing for teachers and speech pathologists to try to get tangled up in all this mess too. So I think avoiding due process and major litigation is really... And I think your Compromise book does a really nice job of leading the way and showing people that you can... I think it may be in that book or... I know in my book, The Verbal Behavior Approach, I put like, I think I cite your book maybe. And I talk about like bringing doughnuts to the IEP meeting. Like you, you still need your pair yourself with the teachers and speech pathologists and, and you still need to be nice because if you just go in there and you're like, he needs this and I can't believe this is the fifth time I asked you... You're not going to be perceived very well and you're not going to get a lot done.

Gary Mayerson: Yeah, I think you make an excellent point. I think that school district administrators by and large are excellent people who are trying to do the right thing. And the same holds true for teachers. I mean, after all, they didn't go into special education in order to hurt children. They're well-intentioned, you know, I think they're better trained today than they ever have been. And what we didn't have when the book was, when my book

first came out some 15 years ago, we didn't have a uniform national standard that was, that was really effective, and that was understandable by parents. You had the rally case and you had the decision from there and there was, there were big questions. That's why you had circuits all over the country coming down with very disparate decisions with different completely different standards. And it was very frustrating to attorneys and parents and school districts that there were no clear guidelines for what does fate mean? What is the substantive right to a free and appropriate public education?

Gary Mayerson: So what has happened since that since then, which completely has changed the field once again, is that we have the Endrew F. Case that came down in 2017. And my friend was actually part of that; the Amicus effort on behalf of Autism Speaks. We submitted a brief on that.

Gary Mayerson: And the Supreme Court for the first time came down and said, Hey, here's what we're going to do nationally. It's no longer just above what's the bare bones minimum, forget that, it has to be robust. It has to be a far more robust standard, has to be challenging for the student and their needs. It has to be, you know, just so much more robust than before. And if you look at the standards, it's a much more outcome oriented test than we had before. So yes, there will continue be disagreement about what fate means. But now that we know that it has to be ambitious and challenging, and i was the first time that the court actually used the word potential. I never saw that before in any decision. So not that the court has to, not that any court is going to maximize a child's potential, but just that they even have to take the child's potential into account. These are all new, you know, new and robust standards.

Mary Barbera: Yeah. Because when I went to due process in 2000, 2001 it was my attorney who said, you know, do not say best, do not, you know, it's appropriate. They are only going to give you the Chevy, not the Cadillac and you know, and as a nurse and a behavior analyst now and you know, I am all about helping kids reach their fullest potential, whatever that is, to be as safe, as independent and as happy as possible. So is it still a bad idea to use the word best?

Gary Mayerson: Well, I think it's a bad idea to make the argument that the reason you're suing the school district is to try to optimize your child's program or make it the best program possible. The Endrew F. Case makes clear that that's not the standard.

Gary Mayerson: But I think it is kinda silly that, you know, what family... Who is shooting for mediocrity? I don't think that's a, you know, not a very good target. I

think that the families and teachers and everybody should shoot for the best, but should understand that if they miss the best and it just happens to fall on what's appropriate and what's meeting the standards, that's okay. That's okay. It's a legal position that you don't want to take because you'll lose your case on that legal position if you say you want what's best for your child. But every parent in the confines of their private discussions, of course they dream about what's best for their child and who doesn't want what's best for their child? That would be silly not to.

Mary Barbera: Right, right. And I'm glad that you mentioned that the Supreme Court case mentioned potential. And I think, you know, the litigation that you've been involved with, other people who've been involved with in the past two decades has helped to end. I think, I don't know a ton about no child left behind, but it did... You know, all the standards, the national standards and just what we've accomplished in the past two decades, some of the studies that have been done showing the effectiveness continued to show the effectiveness of ABA... All of that is helpful in terms of getting kids, keeping the bar raised or raising the bar even if it's not to the best ability, but it's not in the dirt either.

Gary Mayerson: And by using the word potential, I think the Supreme Court is just underscoring the fact that you really need to tease out the child's individual unique needs in developing a program. That's all they're really talking about; not maximizing the potential, but rather using the child's assessed as a guide for IEP development. You know, is it going to be effective to use two or three or four hours or speech therapy? Or are we going to have to go to something like augment of communication, right? Is a behavior plan necessary in order to give the child access to the curriculum so that they're available for learning? These are all part of the, you know, focusing on the child's potential.

Mary Barbera: Yeah, that's great. So you are writing a second book that will be out soon called the Autism's Declaration of Independence. So tell us about that book. How is that different than your first book, and why are you writing it?

Gary Mayerson: Sure. Well, first of all, it's taken way too long for me to write this book. I'm now in like, well into the end of my second year writing it and it was supposed to be ready for the editor probably three months ago. So I'm in trouble with my publisher, but I'm up in Vermont finishing the book this week. So it should be ready for the editor.

Gary Mayerson: And here's why it's different: Autism's Declaration of Independence focuses on basically the ramp up, how to get the best possible outcome

for your child upon the transition to adulthood. I think that so much of our focus as whether as clinicians or as educators is, we're looking at the child that year.

Gary Mayerson: We're focusing way too much on that particular school year as opposed to, taking the long view in making a plan or a series of plans, that will put that child into the best possible place of self-sufficiency and independence when that child graduates from the public school system. So I think that, you know, and I've seen this hundreds of times now where families are doing all they can, the school district is doing what they think is right, and then the child graduates to unemployment.

Gary Mayerson: Necessarily having to live with their parents as opposed to... And that could be a great choice for students too, but not by default. And having a housing crisis and everybody's saying, well they graduated, but what did they graduate to? So the Andrew F. case is part of what they've said, and part of what Congress has said is that they're really focusing on the outcome. We're looking at what is the outcome as the proof of whether the programming and everything that was happening in school was effective. So the book is about how to shape your child's educational program through the assessment process, through using experts, through accessing the programming and the supports that are available in the public school system so that the child is able to graduate to something that's meaningful and fulfilling for them upon the transition to adulthood.

Gary Mayerson: So, so much of what we see today is that you will see conference after conference about transition. That's the issue today. It's no longer... we know that ABA is a demonstrably effective. We don't have to keep that wheel over and over again as we did 15 or 20 years ago. Now it's accepted. The surgeon general has said that it's an effective method. The New York state department of health has a three or four volume set that was published in the 1990s that said it was the effective method. So we don't have to reinvent or fight those, some of those battles again.

Gary Mayerson: We do have to keep sharpening our pencil a little bit so that we have better outcomes for students with autism, whether they are, and I hate this terminology, high-functioning, low-functioning, I don't care about any of that. Wherever the child is, the Supreme Court used the word "potential" meaning that that child has potential. We need to be using that potential to determine what an appropriate and meaningful program is for that child. And we should look at the outcome of how independent we were able to get that student, how self-sufficient we were able to get that student as a measure of our success. Because ultimately we all know how much it costs to sustain a person with autism

who has to live in a group home or in some other similar facility. It's millions of dollars over a lifetime, millions of dollars, and if you're going to invest the money, invest in independence and invest in self-sufficiency that's sustainable and which today we're seeing many more students with autism.

Gary Mayerson: I'm not just talking about Asperger's, but with regular autism, going onto a college experience, and going on to vocational experience. One of the other hats that I wear is I'm the board chair of a non-profit called Job Path, which is located in New York City. And Job Path does what the public school system has pretty much failed to do, which is provide the appropriate vocational training assessment and services so that this student, even if they don't go onto college, has some kind of skill. So these are not just jobs, there are, some of the jobs are, you know, scanning or shredding jobs in offices, but many of them are working in a restaurant preparing food, working in an office putting files together. So you know, today's autism graduate has a future to look forward to in many cases that just didn't exist 10 or 20 years ago.

Gary Mayerson: So I think job development is a gigantic issue when you're talking about an unemployment rate. And we can argue about whether it's 80%, 85% or over 95% but it's way high. It's too high. If you're a typically developing person and you see the unemployment rate going over 5%, you freak. This is at least 80, 85%. It's just unacceptable. But what are we going to do?

Gary Mayerson: As you know... And the book also contains many stories from the cases we've had. Some of the more interesting stories, we have vignettes of what happened in the case, the backstories. I think that a lot of families might find interesting to see what happened in these particular cases. So the book is, it's a different approach. Yes. It has the practical strategies that parents can use if they're at loggerheads with the school district, how to go to mediation, how to send a 10 day letter, how to demand due process, how to settle the case. It has all that, but it has more. And the more is basically the forward looking, looking towards a sustainable future and the transition to adulthood.

Mary Barbera: Yeah. Which is so important. And when you're talking about transition, the transition age when children, when we really are required by law to start looking at it as age 14. But even if you have a 10 year old or 12 year old who is very impaired, you know, instead of arguing and litigating whether they should have this or that, we really also need to be looking at what are they going to do at 16? What are they going to do at 18? Where are they going to do at 25 years of age? Because that should help

shape the IEP because like you said, independence is so important and it is one of the things that I've focused on over the years.

Mary Barbera: The other thing you said is you have this Job Path nonprofit, which is awesome, and I just want to also encourage behavior analysts and teachers listening is you don't have to like send kids to a program, or even have a program already established. You may use ABA principles to go in like I did when I had a sixth grader client and then I had him up through 21, so at age 14 we started looking where is this student going to be able to go for transition trials, for work trials? You know, I didn't have any experience.

Mary Barbera: It's kind of like being a waitress. It's like you just have to start working with where you can volunteer, where you can observe... who's willing? Like the guy at the local restaurant here, he's like, Lucas could come in any time, you know, with his aide, who's not a job coach or anything. But she knows ABA, she knows Lucas, like we'll figure it out. So some of it is just like, because there's just not enough established programs right now to deal with the influx of kids that are going to be coming. And so I really think your book's going to be important.

Mary Barbera: And this podcast is important to tell people, you know, we just need to start developing things based on the individuals that you have and their needs and use the principles. Like when I went into laundry at the hospital, I'm like, show me your, your simplest job, you know. Or with Lucas, he likes to sit to do work versus stand. He's bothered by loud noises. Okay, show me where is the quietest job, where is the simplest job? Where are jobs that you could sit and just start piecing together work trials that can give us data?

Gary Mayerson: Sure. And parents in some instances have to be inventive and creative enough to start their own employment situation completely from scratch. We have a client family that lives in Kodiak Island, Alaska, the Platinum family who... And I say their name only because they've been very outspoken and they've used their name, otherwise it would be confidential of course. But when their son graduated from the public school system and was looking for employment, they came up with a fascinating idea, which is to create, you know, dog tag; lots of dogs in Kodiak Island, right. Dog tags, personalized dog tags and their child was able to start this business and basically be an entrepreneur in an area that wouldn't necessarily have a lot of, you know, regular jobs in office. They don't even have really that many offices in Kodiak Island. There's no ready employment other than the fishing industry, pretty much. It's pretty much fishing oriented.

Gary Mayerson: So, but this is a situation where the family got together and they use their head and they said, you know what, what would be in demand here on Kodiak Island? And dog tags was something that worked for them. So, you know, if you're a parent and you're living in a remote area, don't give up. You may, you can just put on your thinking cap. You may come up with something that people need and that will be a job for your child, or it can be.

Mary Barbera: Yeah. That's excellent. So what do you think are the biggest struggles of facing families of children with autism? And do you find that the struggles change as the child ages?

Gary Mayerson: I think, yeah, I think it also depends on the basic functioning level of the child. So if you are...

Mary Barbera: Well say, say most of my work, my book, my podcast, are moderate severe autism after age five, you know? Or early intervention doesn't matter, what level of autism or even if it's not autism, we treat, you know, pretty aggressive... Moderate severe autism would be where I'd prefer.

Gary Mayerson: I think moderate to severe autism is also probably the sweet spot of what we're talking about with the world of autism anyhow. I think you have to be able... The biggest problem is low expectations. I think that's probably the biggest problem. And we've made some inroads on that. But if you have a school district and you have teachers who are giving up on the moderate to severe and saying, well they're moderate to severe, what do you expect? What do you expect from me? How much can I really do here? And the answer is quite a lot. We, we expect quite a lot. Because I mean if I told you the kind of jobs that I've seen be filled by so-called moderate to severe autism situations, clearly their jobs and expectations that are not being fulfilled.

Gary Mayerson: So I think low expectations is an ongoing problem. It's better today than it used to be. Funding is also a problem because when the legislature's see the words moderate to severe, they're the same thing. Like, I want to be putting my money where it could really, it might, it might, you know, make a difference. And they think that the only place to do that is to put point all their money towards the so-called high functioning and more mainstream oriented student. And so that's a problem is you have to fight the funding mechanisms.

Gary Mayerson: We also have, you know, a lot of infighting right now. The idea statute was a bipartisan effort. It was a beautiful statue. And if you see the

Republicans, the Democrats that work together so effectively to put that and to see what's going on today, it's a problem. It's a problem. So that when funding has to be approved for certain programs, this partisan stuff comes into play and it can be a real serious problem.

Gary Mayerson: What else? I think that...

Mary Barbera: Do you think that these struggles change as the children ages, or you think it's just funding expectations?

Gary Mayerson: I think that depending on what happens with the economy, when the economy is great, we have the least amount of problems, but we still have problems. So I'm always concerned that there shouldn't be a recession in the works because if you have a recession and... I'm not saying we're going to definitely have one, but I see a lot of articles pointing in that direction. There'll be some retreating of the economy. That's when, you know, my grandmother used to say when the wolf is at the door, love goes out the window. Yeah. My Hungarian grandmother, she was right. And I think that when there's that threat that this kind of funding is the first to go, and some legislators have no problem balancing a budget on the back of a child. So we have to be, you know, as a group, we have to be very outspoken that we can't allow our funding to be, to be interfered with. That's if it's important funding that we rely upon.

Gary Mayerson: I think one of the biggest problems facing the group that the moderate to severe is that what's going to happen upon the transition to adulthood in terms of their living arrangements? It is one thing, as I said before, to choose living at home. But that's not a sustainable arrangement. No, we parents might like to want to live forever to protect our children, but we're not going to be around forever. That's the reality.

Gary Mayerson: So there has to be funding, there has to be opportunity to have... living arrangements that are sustainable if we're not here. I think that's something that keeps a lot of our client families up at night staring at the ceiling at two o'clock in the morning. And it, you know, even in the so-called good states, it's very difficult to find these housing scenarios in there. There's a certain amount of Medicaid money that, and a certain amount of state funding that every state has its own formula.

Gary Mayerson: And I think that that housing crisis is here. It's now and it will continue until we do something about it. And it can't just be, we're going to ameliorate it by just making people live with their parents. Because that's one part of an effective strategy, and many parents want to have their

children living with them and the children want to live at home. That's fine. But as I said, it's not sustainable for the future.

Mary Barbera: Yeah. And with the influx it's just going to get worse and worse. And I had a couple of podcast guests on so far. Amy... I'm blanking on her last name. Oh, she talked about severe autism and transitioning to adulthood. And yeah, it's just a huge issue. I know. What do you think are the biggest struggles facing school districts?

Gary Mayerson: I think that, as I said, I give a lot of credit to school districts. We're doing a lot more today than they were doing 15 or 20 years ago. Training is a big issue. Training is a big issue. And I think that there are policies, a union, sometimes there are union policies that can come into play and ruin everything. I'm not anti-union. You know, I come from a working family back to my grandparents. They were very, they were union people, but I think that there's too many union restrictions that interfere with the education of children with developmental disabilities, including autism.

Gary Mayerson: Autism is a 24/7 workaholic... workaholic for sure. And either you're working on it or it's working on the student. And I think that, you know, too many union rules are like, well it's 2:30. It's over, we're done for the day, go home. And there are other union restrictions in terms of like... For example, lunch can be a tremendous social opportunity for learning lots of social skills. That's where the social skills are practiced. And yet too many times I'll see a situation where it's like, well, the teacher is not going to be at lunch. They're not on lunch. They're going to be in the other room where the teachers are having lunch. Well, who's going to instruct the student in terms of where to sit, how to get a conversation going and so forth? If there's no adults in the room and it can't be the union rule that prohibits or prevents that from happening.

Gary Mayerson: That's just one example of, you know, we sometimes see the union come in and it's like we just roll our eyes. Like the idea statute does not say you have to do this, this, and that. Unless the union objects, it doesn't say that it's a federal law. And too many school systems don't want to take on the union. So they just sort of quietly let the policy go by. You know, funding is still an issue. School districts are always worried about how are we going to get the money? They know that it's, part of it is federal funding and part of it is state funding. The idea statute was supposed to be 40% funded by the federal government. It's still not at 40%, and the price tag of the cost of all this keep going up and up.

Gary Mayerson: So I feel for school districts they don't want to rate keep raising their property taxes. It's just because what happens is you get a resentment

factor in any school district where you will go to a school district meeting and somebody will say, well these are the mandates. And some families you'll see somebody stand up and say why do we have to pay for all these aids and why do we have to pay for all this? And there's a growing resentment in some school systems that make the parents of special needs children feel like pariahs. So that's a terrible problem. You should be lucky that your child is not need is not needing this extra funding and you should be supportive. You know, obviously I'm preaching to the choir here, but I see that this kind of conflict happened quite a bit.

Mary Barbera: I do too. And we do, I think like you said, your first book as well as it sounds like your second book is really going to address not just the parents and what they can do, but also, you know, some definite help for the school districts in terms of planning and how we can all work together to get kids to their highest potential and it's gonna take a village.

Gary Mayerson: I agree. I agree. And then I think the book is not just for parents, it is also for school district administrators and teachers. Because as you point out, we really are all part of the same team. We're supposed to be. We're supposed to be rowing the same boat in the same direction. If we do it right we will have different outcomes upon the transition to adulthood. That will happen.

Mary Barbera: Great. Well I want to wrap it up, but before I do that, I want to thank you for joining us. But one question I usually end with, which I think is a good ending is my podcast, part of my podcast goal is for parents and professionals to be less stressed and lead happier lives. So do you have any advice for our listeners on how they can reduce their stress and, and be happier?

Gary Mayerson: I think, I don't know. I'm not, this is not my field, it's above, my pay grade, but I think that when parents, you know when you're on the airplane and God forbid there's a problem, but the plane is going down or there's an oxygen problem, there is a sign that says, make sure that put the oxygen mask on your face before you do anything to help your child. And I think that because we're talking about the long game here, we're taking the long view. It's not just one school year, it's, it's years and years and years before the graduation from the public school system. I think that parents have to pace themselves and they have to pace themselves by giving to themselves as well as their children and not be ascetics and not be martyrs because that doesn't help. That will not work and it will not be sustainable. So I, you know, even a little thing if a parent can take off some time for themselves, I'm not suggesting that all parents can go to

spas or can take vacations. Many parents don't have that kind of money, but there are little things that parents can do to give to themselves and they shouldn't feel guilty about taking a break. You shouldn't feel at all guilty about it.

Mary Barbera: Right. I think that's excellent advice. So thank you so much. I learned a lot. And if you are listening and you have any interest in finding out more about my online courses and community, whether you're a parent or professional; toddler through teen, you can attend a free online workshop at marybarbera.com/workshop. So thank you so much, Gary, and I hope to connect with you soon in the future and in many endeavors coming up.

Gary Mayerson: Thanks for having me.

Thanks for listening to the Turn Autism Around podcast with Dr. Mary Barbera. For more information, visit Marybarbera.com.