

Transcript for Podcast Episode: 048

Autism and Picky Eating: 7 Feeding Tips to Solve Feeding Problems

Hosted by: Dr. Mary Barbera

You're listening to the Turn Autism Around podcast, episode number 48, and today I'm talking all about picky eating and children with autism. And if you are a parent or professional, I'm sure that your children and clients have some kind of picky eating problem, or they may have had picky eating in the past, but it's very common among children with autism to be picky eaters. So today I'm going to give you seven tips for both parents and professionals. So let's get to those.

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.

Welcome back to the Turn Autism Around podcast. I'm your host, Dr. Mary Barbera. And before we get started with some of my background in feeding issues and as well as the seven tips that I hope will really be helpful to you, I do want to say that all the information in all of my podcasts, all of my video blogs, and even in my paid online courses, all of the information is for informational purposes only. I've been a registered nurse for over 30 years; I've been a board certified behavior analyst since 2003; and an autism mom for over two decades. And I am presenting information not as medical or behavioral advice. Only a qualified medical or behavioral professional who actually assesses your child can make accurate recommendations. So these are just general tips that have helped a lot of people and maybe the tips will lead you to believe that there is a more serious feeding disorder, which is very common in children with autism.

So eating problems in general, I want to give an extra disclaimer that eating disorders can lead to malnutrition. Chewing, swallowing problems can lead to choking even major problem behaviors during feeding can lead to very significant issues. So when in doubt, it's best to get some professional help and guidance. But I'm hoping these seven tips will help you first determine if this is a serious issue; and second we'll give you some recommendations that you can begin to gather some data. Don't get freaked out by the word data. I mean, just some easy information that you can bring to those medical and behavioral professionals that you are going to be seeking.

So I will get started by telling you that I had issues with Lucas when he was two and three years of age. He was very picky. He was diagnosed one day before his third birthday, and from three to four he became more picky as we were working on getting ABA set up and he was starting to only eat McDonald's fries. He was starting to eat only the edges of the crunchy part of chicken nuggets. And so I didn't know, as a registered nurse, really how to deal with that. And my ABA providers were not diving into the feeding issues.

Lucas did have some malnutrition from what the doctor said based on his weight and height, to the point where he was willing to recommend him for a behavioral outpatient clinic at children's hospital in Philadelphia. So we drove back and forth, I live about an hour and a half from Philadelphia, driving back and forth each day for 10 days to deal with Lucas's picky eating. And that was a behavioral program. It was run, not sure if it was run by a behavioral analysts... were just becoming a thing actually when Lucas was four and a half. So it wasn't a behavior analyst, it was probably just a psychologist with feeding expertise. And I learned a lot there and Lucas did come out of there eating a variety of foods. It was like a crash course in those 10 days.

And then added to my experience as a registered nurse where I was working for over a decade with neurologically impaired patients, like patients with strokes, head injuries, spinal cord injuries. So we, I worked in rehab, I worked in an acute hospitalization. So we always worked on feeding and multidisciplinary evaluations and goals and you know, soft foods progressing up to more solid foods and those sorts of things. So feeding was always high on our radar when I was a registered nurse. So that, and then added to my feeding expertise if you will, was that 10 day experience at children's hospital with Lucas.

But I really didn't start to really work with treating feeding disorders myself until about 2010 when I left the Pattan Verbal Behavior project and started out with a birth to three contract in my County.

So there I was faced with pretty much any child that was sent my way had some kind of feeding issue. So I remember the first two clients I had in the early intervention system, one boy was banging his head on hard surfaces three hours a day, to the point where he got an open wound on his head. He had feeding problems but that wasn't really high on our list to treat. His feeding problems weren't as severe as another little boy that I started with just a week or two after. And this little boy, I'll call him Billy, he was also too just diagnosed with autism, and he would only drink almond milk out of a bottle and eat gluten free crackers. Mom had read about gluten casein free diet. She had started that. I'm not sure how long he had been on that, but he was so selective that he was, that was all he was eating and drinking, morning, noon and night. Except for occasionally he would like McDonald's fries. And so if they drove through, if they were hot, if he was hungry and if they were in the right container, Billy would eat the fries as well.

So just getting back to some of the research that goes to show that kids with autism are at risk of having eating disorders and being extremely selective in their feeding. Dr. Kim Schreck, Keith Williams, and Dr. Smith published really a landmark study... I believe it was 2004, and then Dr. Williams and Dr. Fox also published a book on eating disorders and that was in 2007. But the

2004 article by Schreck, Williams, and Smith, which we will link in the show notes... And when I say link in the show notes, to get to those show notes for this episode, this episode is 48 so you would go to Marybarbera.com/8 to get anything I'm mentioning today in this podcast.

But that article was a study of 1000 families, kids and their parents. And I actually remember participating in that study in 2004. And they looked at what the parents ate. So whether I ate fruits and vegetables every day. Yes, yes, yes. And then whether Lucas ate fruits and vegetables. I think it also maybe compared it to any other kids in the household. So whether Spencer ate... Or maybe it was just the parents and the affected child with autism. But what they found was it wasn't because the families didn't offer or didn't have available fruits and vegetables; it was something within kids with autism that was making them highly selective to carbs and to white food and to crunchy food. So that's a fascinating study. You can read it by going to the show notes on episode 48. Okay.

And I'll also link Keith Williams and Richard Fox's book in 2007 which is an awesome book. It's pretty pricey. It was pricey. What back when I got it years ago and now it seems like it's even more pricey. If you are a professional in the field, you'll want to get the Williams and Fox eating disorder book if you can. Okay.

So getting back to my initial experience with Billy and the other boy that was banging his head, we learned, I learned pretty quickly that if I saw a feeding issue, I also almost always saw a talking issue. I also saw a problem behavior issue in a lot of cases as well. And in the birth to three system, at least in my County, the occupational therapist and or the speech language pathologist was the one in charge of any feeding goals. And even the kids who couldn't tolerate, who were just very selective and had problem behaviors with that selectivity.

So when I started with a little boy, I'll call him James, he was two, just diagnosed as well. So I started, he already had an OT in place, he already had a speech therapist in place, and the OT was in charge of the feeding goal for him. And he could not tolerate... He would eat and chew and swallow finger foods, even vegetables. He would eat a string bean, he would eat chicken, he would eat, you know, a few different things, but it couldn't be on a spoon, and it couldn't be mushy inside. So even just presenting him with Apple sauce in a bowl freaked him out. I didn't know this for the first couple of weeks that I was there. I was trying to pair up the little learning table. I was trying to pair up the materials. I was having a lot of problems where I couldn't get James to, you know, to come and I asked to see his feeding and it was kind of a disaster because I, even when I was told that wasn't my goal, I wasn't allowed to work on that, in so many words.

Then I asked to have a joint session with the occupational therapist and myself. And so I basically said, well, okay, so what's your plan? And she would push applesauce in front of him and he would scream and she would pull the applesauce back. And as a behavior analyst, I knew that was very bad shaping in terms of, we do not want him screaming during meals period, but we want him to be able to tolerate even the sight of mushy foods and we want them to tolerate spoons and eventually forks.

So to make the story shorter, I basically took control of the feeding goal and we worked on that, and that was really tied into his talking and to his oral motor language. We also worked with Mags Kirk who did a podcast episode a few months ago, and we can link that in the show notes. I don't remember what that episode number was called, but Mags Kirk is a speech and language pathologist and she is a new BCPA and she is an expert in Talk Tools. And so what we found with James is a lot of the chewing and the selectivity problems were all related to his oral motor system and that he actually needed work with a different talk tools equipment. And James did eventually become more vocal, but it took some time. But in the meantime we got him, we actually got him to start tolerating spoons, not with mushy food, like applesauce. We got him actually tolerating spoons and being spoonfed with things like corn chips to start.

So there's definitely a lot to it. And within my online courses, both my toddler preschooler course for parents and early intervention professionals as well as my verbal behavior bundle of courses, there are videos of me showing videos of kids like James and Billy. I've changed her names for this public episode, but there are videos of me actually over time coaching the parents to get the picky eating under control. So and to find out more about how you can see if an online course in community is the right fit for you, you can always go to a free online workshop at marybarbara.com/workshop. We will link that as well in the show notes.

But I do want to tell you about, you know, the seven tips with these couple of kids, Lucas, Billy, James, I also want to talk to you about a real briefly before we get into the seven tips about a little boy. I'll call him Todd. And he was actually 10 years old. He was five years old by the time I saw him the first time. But I then saw him every couple of years for independent evaluations. And the last time I saw him officially was 10, and at that point he was very picky. He was eating every meal on the sofa in the family room. He was not eating with his family at a kitchen table. Therefore he was eating finger foods where he was able to pick the stuff up himself. He was not using utensils. He was having free access during all meals to a stack of DVDs and a remote that he could control, which led to high rates of self-stimulatory behavior.

And so, I know over the years, even with Lucas who's now in his twenties, you know, we've worked on now, you know, years ago we worked on cutting with a knife and a fork. And, and so he has very good eating behaviors now, although he still has reverted back to a pretty selective things he will eat. And it's just a matter of if I have the time and the energy, I could get him to eat anything. It's just, you know, I want him to be happy. I want him to be comfortable, and we want to prevent kids like Todd, who's 10 years old, eating every meal on the sofa, not able to use utensils and that sorta thing. So for every family it's going to have a different priority level. But these are the seven tips that I would start with my clients, with my son, to gradually get it to be better. Getting the feeding issues to be better, whatever better means we, I'm all about helping each child reach his or her fullest potential; Be as happy as possible, as safe as possible and independent as possible.

And so everybody's gonna be kind of at a different level. But if you're having feeding issues and picky eating, then hopefully these seven tips will help.

Okay, first tip. And if you've listened to anything else I've ever recorded, it always starts with the same first tip is you always have to start with assessment. Hopefully we're filling in the blank to that. So assessment is so key because like I just said, I just described a handful of clients and my son, and my son at four, and my son in his twenties; they're all going to be at different levels. They're all gonna have different needs when it comes to feeding and different issues. So the number one thing you want to do is create an assessment or do an assessment. If you want to see if you need to change the behavior, you can also determine how serious of an issue it is. So the first assessment, I'm going to talk about two assessments you can do... This is all tip number one.

So the first assessment is for three days you, or if you're working with a family, have a parent write down everything the child eats and drinks that has calories. So if they eat 10 chips, if they eat four ounces of two milk, if they eat four ounces of grilled chicken, you know, be as specific as possible. Have them write that down for you. Three days of assessment. This way you'll be able to tell a lot of things. You'll be able to tell, you know, a general ballpark of how many calories they're getting, how many foods or you know, with Billy for instance, we would have just had like almond milk, almond milk, gluten-free cracker, one whole one, you know, those sorts of things. So you write that down so that you can analyze your baseline data, where you're going to start.

The second assessment that I would highly recommend, which we will link in the show notes, Marybarbera.com/48, will be Dr. Mark Sundberg's self-care assessment checklist. This is based on chronologically, typically developing kids, so at an 18 month old level, for instance, kids, typically developing kids should be drinking out of an open cup and drinking from a straw. If they're three and they're not, or they're two and they're not drinking out of an open cup and a straw that would be, you know, something to work on. 30 to 48 months, they should start to use your utensils. Start to cut, things start to eat with a fork.

Okay, so two assessments that baseline data for three days preferably, and the self-care checklist. There's a feeding part of the self-care checklist in which you'd want to complete. But I would also do the grooming and the potty and the other parts of that self-care checklist as well. Okay.

Tip number two is you make three lists on a piece of paper. Once you have your three day assessment, you also have the parent work with you if you're a professional, or if you're on your own as a parent, make three lists on a piece of paper.

On the left hand column you want to list easy foods. Your child eats or drinks these, no problem. That's their favorites. Okay? Those are easy foods and drinks. List them in the easy. In the medium column, which is in the middle, you're going to list medium foods like your child has eaten them within the last month or two, but they might be like brand specific, like only if it's french fries from McDonald's in the carton and they're hot. So he wouldn't have it in the easy column because if he would eat french fries, any kind of french fries, if you made them at home, if they were fried, if they were baked, if they were different brands that would go in the

easy column. But kids with autism tend to be brand specific. So if there's something specific that needs to happen, like they will only eat Kraft macaroni and cheese in a blue bowl that would go in the medium category. You're not going to be able to expand that at the moment.

And then in the right hand column, you would put hard foods. These are foods that you'd want your child to eat. Maybe they ate them more than six months ago or more than two months ago, but they would really fuss if you tried to get that to them at this point. So for now, that's, that's tip number two is that's kind of more assessment. But you're going to group these, these foods into categories. Easy, medium, and hard. Okay?

Tip three is the child should be sitting for all meals and snacks at a table; not like Todd did by eating on a couch. They should be coming to the table and they should be eating there. Not allowed to graze throughout the day, not free access to grab, you know, the goldfish crackers and be eating them out of the package. They should be served at a table sitting in a chair. Okay.

Tip number four is we want to change the snacks and meals to be as nutritious as possible. So you know, if on your easy column is grapes and maybe celery sticks, but also on your easy column is goldfish crackers and pretzels, and junk food, then we're going to want to really increase, even if it's serving celery a lot and serving grapes a lot we want to get the snacks and the meals to be as nutritious as possible.

Tip number five is we want to limit snacks in between meals in general, but especially an hour before and an hour after. I remember being down at that 10 day outpatient feeding program at CHOP and Lucas was not allowed to have anything to eat or drink besides water for one hour before the feeding started and one hour after. And you know, kids can fill up before. I remember working with one of my clients and he was being watched by a grandmother and the grandmother would, you know, well, he didn't eat anything that I fed him. So I let him have two bowls of fruit loops after we tried, you know. And if the child knows like, Hey, I can always make myself a peanut butter and jelly sandwich or I can, I know mom will be worried about my weight. So you know, I'll just hold out, I'll refuse the meal and then I'll get, I'll get something, you know, later. So we want to stop that ability to graze, ability to get the stuff, especially outside of within one hour before and after meals.

I remember Dr. Keith Williams when I had the opportunity, many of my early intervention clients, we actually, I was involved with going to Dr. Keith Williams clinic at Hershey medical center. He gets people from around the world. They're fascinating. I was able to go with them for some of their visits. I was able to read his plan. He would make a one page plan. I was able to help the families implement the plan, keep an eye on things to the point where, you know, Billy and the other children, maybe a handful of children I worked with from 2010 to say 2014, we would go to the clinic and I would go and I would implement. And that was furthering my training on feeding disorders. And then for kids like James and those that came after, I was able to actually treat them without going to Dr. Williams. But I remember Dr. Williams saying for one

of the clients, you know, she's no withering flower. Like nobody's going to starve to death from refusing dinner till the next morning.

So sometimes you have to hold out a little bit more. So, and you want kids to really be hungry when it is time for snacks and meals. Not that we want to starve kids or withhold anything, but just to be aware, like if you're filling up with junk throughout the day, you're probably not going to be that willing to try new foods. Okay. So limiting, limiting those snacks is really big. Okay.

Number six, we're getting towards the seventh one. It's also important to look at drinks. Anything besides water and any drinks that are in bottles or even spill proof sippy cups can affect talking. They can affect your dental, your teeth coming in. Pacifiers are a problem too, even though that's nothing, you know, food related. But bottles definitely like with Billy, weaning from a bottle was a big deal. Also weaning off of spill proof sippy cups in general can help articulation. I talk about that a little bit in chapter six of my book, The Verbal Behavior Approach, too.

And we also have a, if you're struggling with a child over the age of one and you need to wean them from bottles or even pacifiers, we do have ditch the bottle and pacifier a free cheat sheet if you will. And that we will link in the show notes as well. That's Marybarbera.com/ditch, for ditch the bottles and pacifiers. Those are six steps to help you wean if you're struggling with that.

But whether it's a cup or a straw, a sippy cup, spill proof that would be my preference. But really only water throughout the day in between meals and snacks. Because if you're serving milk and juice and calorie dense drinks, that's also going to affect their picky eating. And you might have to go gradually. You may have to start ever so slightly watering down the juice to get it more like water and less like juice. We don't want to spur up big problem behaviors, so gradual is better and you may want to download that Ditch the bottle and pacifier. Okay.

We are at our final step, which is to start presenting. So you have your easy foods going, the child sitting at the table, they're not grazing throughout the day. They're off bottles and spilled proof sippy cups. They're starting to accept easy foods and maybe you can start merging in some medium foods. So that for Billy for instance, he used to, in addition to his almond milk in a bottle and gluten free crackers, he used to tolerate or like McDonald's fries if they were hot and in the right container. We started when we started with Dr. Williams, we started making fries at home and that soon became an easy preferred food too. And so they didn't have to be fried, they didn't have to be from McDonald's. And one of the other keys is when you are presenting these easy and medium foods, it's really important to get them out of the containers. So if they only like Yo Play Yogurt or something like that, scoop everything out while it's easy into neutral bowls so that they don't get brand specific. That way you'll be able to bring in different brands and different types of things.

And this will help as you eat out and child begins to eat at school in the cafeteria. So gradually start presenting your medium foods and your harder foods as tolerated. And like I said, if it's a

serious enough issue, definitely refer yourself. The way I usually refer, recommend people find a feeding clinic is to look at a hospital, a children's hospital that's closest to you and look for a feeding program and preferably a behaviorally based feeding program. We did take those first two clients to a multidisciplinary more oral motor feeding program. It didn't work. It was like the techniques like playing with noodles or tolerating the sight of applesauce for a kid like James and it just really did not produce results in kids with more severe problem behaviors related to being picky and food selectively issues.

So in summary, we want to do an assessment including the three day assessment where you write everything down and the self-care checklist. We want to make lists of easy, medium and hard foods and we want to keep all meals, drinks and snacks as nutritious as possible at the table. Avoiding like the constant filling up in between so you can continue to avoid the nutritious food that children need. And in general, if a child is having feeding problems, they are probably having some talking problems, problem behaviors, problems with imitation, play, self-care, and that can really only be addressed as a whole unit. That's why I created all of my resources, my free resources like these podcasts and video blogs, as well as my paid online courses and community. Again, you can find out more about that at marybarbera.com/workshop.

I hope these tips have helped you become more aware of things you can do, whether you're a parent or professional, to help kids with picky eating and autism. And I hope you enjoyed it. If you did, I'd love it if you would go to Apple podcasts or wherever you're listening, give me a five star review, and hope to see you or hope you hear me next week for another episode of the Turn Autism Around podcast. Have a great one.

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