Empowerment Strategies for ASD Parents: More Than Just Coping

Chantal Sicile-Kira

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Guest Speaker: Chantal Sicile-Kira

Good morning and welcome to Get Educated About Autism and Autism Awareness Conference put on by momsfightingautism.com and co-sponsored by AutismCollege.com. I’m Chantal Sicile-Kira. I am presenting this morning on "Empowerment Strategies for Parents: More Than Just Coping." I’m also the founder of Autism College and author of numerous books on autism.

So welcome to this presentation. If you want to send in questions, you can type in questions
or I can take call-in questions. You push *2 and when I see that somebody wants to ask a question, I’ll check like every 10 minutes or so on that part of the PowerPoint presentation technical aspects that I have here which is not my strong place but I’m sure I’ll get through it. So just bear with me in terms of the answering live questions on the phone. But I know how to do the answering questions that are written for sure, so not a problem.

Welcome to those who have joined. And as I’ve said, I’m speaking bout Empowerment Strategies for Parents. My new online resource is Autism College and I just wanted to mention that starting in May, I will have a 4-week, 2-hour a week empowerment strategies course and I’ll be giving a lot more practical invites that I’m giving here. Today, we’re going to be talking mainly about attitude, but in this course which is 8 hours total, I will be giving a lot more information such as becoming an advocate to your child and the strategies needed like good negotiation skills, communication skills, how to adapt to change and develop new skills, how autism affects the family, and how to help with all of that, coping with life with autism as a family and creating supports and taking care of yourself.

So today, we’re going to be talking mostly about acknowledging and dealing with the emotions of having a child with autism. Okay, and these are the covers of my books. I have written 4. I’m co-authoring a fifth one with my son, Jeremy, “A Full Life With Autism” that’s going to be about adult services and creating an adult life that someone with autism would like and how a parent can go ahead and helps to do that because for those who have children nearing the adults ages, that’s a very difficult arena. And so Jeremy and I have co-authored this book which will be published next April. So we look forward to sharing more about that at a later time.

So great expectations versus the grief cycle is going to be the first topic that I’ll discuss here today. And what do I mean by great expectations versus the grief cycle? Well, when you’re expecting a baby, you have all these ideas of what the baby is going to be like. Some people already know whether it’s going to be a boy or girl. I never wanted to know ahead of time. I sort of felt like it was Christmas. If I knew, those last couple of months when you’re so tired to being pregnant, I thought if I’d know what’s inside already whether it’s a boy or girl, it’s going to ruin the last couple of months for me. At least I have a surprise to look forward to. But boy, the surprise I got was not the surprise I was expecting.

So anyway, great expectations or all these ideas that you have is that the child or the baby that you’re awaiting. If you’re a mom and you really like ballet and you like baking and you like girl scouts and you like all these kinds of things, you are projecting these ideas of what it is that you think your child would enjoy doing and what you want to share with your child. And then, if you’re a dad, if you’re into baseball or you’re into soccer or you’re into athletic for some time or you’re really into building things in the garage, that’s something that you hope
to share with your son.

So it’s these ideas of great expectations also of what will this child become. And you know, usually those parents who have the neuro-typical kids and especially today, it’s so competitive. Everyone thinks their child’s the top of the class, their child has to be at the top of the class, they can’t just play on the baseball team, it has to be the competitive baseball team, kids have so much time—not the kids with autism on therapy who are busy with therapy, but the neuro-typical kids are so busy excelling to be the best at everything because of their parent’s great expectations.

And then you have the grief cycle, which is what normally we think about when there’s a death in the family. And so the grief cycle that families with autism go through has been likened to the grief cycle that people who lose a family member go through. So there’s all these different parts of the grief cycle that we are grieving as parents with autism because of the death supposedly of these great expectations.

“Disappointment is a sort of bankruptcy – the bankruptcy of a soul that expends too much in hope and expectation.” And that kind of what part of our challenges as parents of autism is that, especially for those who have had a child that developed normally and then regressed. Jeremy, when he was born, he seemed to be pretty normal. But you know, within the first couple of months, I could tell because I’ve worked with people with developmental disabilities before Jeremy, and I had babysat a lot and I have 5 brothers and sisters, so I knew kids. And I thought this kid is just not, this baby is not progressing the way that he should because he didn’t do all the things physically or motor-wise that a baby should. But there are those whose kids develop normally and they connect with their child like any other child and then after something, for some people’s vaccine, for some people it’s other things, whatever the reason, there’s a regression that takes place. And they lose the child they got to know. So that’s another type of disappointment, but they’re both disappointments.

And this bankruptcy of the soul is because as I talked about in the great expectations, you expect and you hope so much for this child and this relationship that you’re going to have with the child. And then that disappointment sets in. And the thing about the disappointment is it’s really a bankruptcy in the sense that we are spending too much energy and time in hope and expectation which is normal. I mean that’s what you do, you hope and expect about things.

But it kind of reminds me about a friend I have who also comes from a large family but he didn’t have such a happy large family. My large family, well my family is pretty dysfunctional. They weren’t normal at all in the sense that they were French and we were raised very French in America. They weren’t your typical American family but we were very
close in the family. Okay. And this friend of mine had a family where he went through a few
dads and the last dad was abusive and an alcoholic and so he had a really rough time
growing up with the dads who weren’t always the best role models and were not very good
with all of the kids.

And so I remember, you know, we always talked about our holiday dinners and our getting
together with the family at Thanksgiving and Christmas and so on, and how we were always
disappointed after these holidays because, you know, they always ended up being somebody
fighting with somebody or somebody arguing with somebody or everybody afraid of dad, and
so everyone being on their misbehavior but, you know, somebody being in a bad mood. You
know, so you always felt disappointed after these encounters. Sort of like when you have
your child with autism and you try to hope that it’s going to fit in to the holiday and it doesn’t
fit in to the holiday celebration with the family, there’s a disappointment afterwards.

And my friend, when I was talking about this fact about the family, you know, we used to
exchange stories, he said to me one day, “You know what, the problem is that you have
expectations. If you don’t expect anything from these holiday reunions and how the dinner is
going to go, then you won’t feel disappointed.” And I thought huh, that’s really cool way of
thinking about it and then it’s true. After that, I really worked on not having expectations
about this family get together with everybody, and so I didn’t have the expectations and
everything seems better because I didn’t have this ideal family holiday celebration that I was
holding up what actually happens against.

And so it’s the same thing with having a child is that we hope and expect so much and then
we are very disappointed because the child is not what we expected but I think the part
that’s important to realize is that when you decide to have a baby, there are certain things
you have no control over. Okay, an so especially for those of us who have kids like Jeremy
who was never developed in a normal developmental way, you decide to have a baby and
you have to accept and love the baby that you have. You can’t hope and expect for
something that you have no control over. It’s not like you’re going to the store and buying a
TV set that has warranties and guarantees. Now, in saying that, I’m not saying that you
accept, meaning, you do nothing about it. I mean, anybody who knows my story and
Jeremy’s story will know that I didn’t sit back and accept that my son would go to an
institution which is what they were told us that would happen to him or that I should start
looking for an institution right away when I had his diagnosis at the age of 3. So actually,
he’s in an institution and that’s called “college.” And so that’s the kind of thing that’s
important to think about.

So how do we handle this? We acknowledge the emotions including grief that we feel. It’s
really important. I remember the very beginning with Jeremy for the first, oh gosh, maybe
even 4 or 5 years. I was very much into being a goal-driven person. I’m still very goal-driven, but I just thought you know, if I do this and I do this and I do this, Jeremy is going to get better. You know, Jeremy is going to have control of his muscles, Jeremy is going to be able to learn this, this, this. If I do 40 hours of ABA, it’s going to work, this is what’s going to happen. And I totally did not acknowledge the emotional aspects of the diagnosis of having a child like Jeremy. And so it’s really important that we take the time to acknowledge the emotions including grief and that you acknowledge that the grief is not that you don’t have a child anymore. The grief is that you have a loss of expectation, because you have to get away and you have to get rid of all those expectations that you have. Now, I don’t mean that you don’t expect that your child is going to get better or recover if that’s what’s you’re going for or that he’s going to make lots of progress forward and forward and forward. But the point is that you have to do everything you can to help your child but you can’t have expectations. And that grief that you’re feeling is the loss of the expectations that you had for your child’s when your child was still healthy or when your child was still in the mom’s tummy. And so that’s the kind of thing you have to realize that you didn’t lose a child, you lost the expectations that you had for this child. And so you need to revisit those expectations.

Yet the challenge and notion of a never-ending grief cycle and what I mean by that is that everyone talked about the grief cycle, the grief, the loss of a person close to you, and being what we experience in autism. And I want to challenge that in the sense of I do believe we go through a disappointment, we go through grieving, we go through depression, we go through all these different emotions, but I don’t think that it really should be a never-ending grief cycle where it keeps going on and on and on that you never get off of this cycle. I don’t feel that that’s true. I feel that over time, you learn to handle the emotions and you realize that you know, even though you never stop hoping and you never stop helping your child to be the best that he can be, you are not always on this never-ending grief cycle.

When I think of grief now or when I think of being disappointed or depressed or unhappy, it’s not about my son. It’s about the systems that are in place that are making life so difficult for us to get any kind of help. That for me is grief, my grief. Jeremy is not my grief. It’s the systems in place and that’s a whole other topic from another story.

So one way of doing, of handling these feelings that we have is to analyze your expectations and what values they are based on and create the new great expectations based on those same values. And what I mean by that is that if your expectations for your son, let’s say you’re a dad and you expected that your child was going to play football because you love football, well why is it that they were going to play football? Is it because you were the quarterback on your high school team and that you loved playing football in that sense that you have to strive to be the best football player? Is it because you wanted to share and just
passing the ball around with your child because you just found that fun? Or is it because you wanted to sit and watch football because you really like the game? Well, if your child is, you can try it and do those things with your child, but if it doesn’t work out, you have to find other things that you two can share.

And you know what, this would happen if you have a neuro-typical child anyway. For example, my daughter is very athletic and she is not an all girly girl and, but she’s not athletic in the areas that I am like I love running. That’s what I do. And Rebecca hates running. So she loves playing tennis, she loves playing soccer, she loves playing basketball, all these things that I’m not good at because I’m so uncoordinated, it’s not funny. Yet Rebecca will not want to run, never wants to run. I can barely get her to go for a walk with me. And so I have to think about other things that I can share with her.

So the same thing with a child with autism. So in our family, physical activity is really important. Jeremy, we try to get him to learn how to ride a bike because we figure that’s one thing, he likes wheels that turn, he likes movement, he likes speed. We can ride bikes together. That can be a family way of doing healthy exercise even though bicycle running is something everyone in the family has on what’s in our favorite activity. So we thought this is something we can do together.

Well, we were able to teach Jeremy over 2 to 3 years with lots of help from different people how to pedal a bicycle but without the training wheels but the problem is he never understood steering. He never got to steer. So what did we do? We got to tandem. So he sits in the back. It doesn’t matter if he can steer or not, but we can still ride the bike around and the four of us would go out and ride bikes and that was our way of sharing family time together and doing something healthy.

Before I continue and this is going to go over to the question area and see if there are lots of questions or not. There is a couple, but I’m going to continue right now. Is anyone seeing the slides okay? I hope I’m doing them okay. I hope I’m moving them the correct way. Okay. So back to the slides. So thinking about the great expectations that you can share with your family that you can create.

So the next one I wanted to make is the scarlet letter A. Do you remember the story about in the, I don’t even remember what year it was but in the old days where there were women that they were thought to be adulterous. They had to wear a scarlet letter A on their forehead. And sometimes I feel there were years when that’s what I felt like no matter where I went, I had the scarlet A but for autism on my forehead and I always hear about parents who were really embarrassed out of public because they are worried about what their child is going to do and I remember being that way to. But I think I felt that less than some
people because my family growing up French in America and my parents used to embarrass us all the time by making us do French things all the time, go singing French in front of community organizations and we have to wear the same outfits, and I always, you know, we were always the French family no matter where we live because we move every 3 years because my father is a project manager and so we were that French family, you know, always full of French kids. So it’s that family that always speaks French and does everything French. So I always got used to being looked at as something different. And then when I moved to France, I was dispersed and we spoke really excellent French but with a tinge of an American accent and she did things a little weird like an American so she was the American.

So I’ve always had attention drawn to me for not necessarily positive traits always. So once I had Jeremy and I was out and about with him, I think it was less embarrassing for me than for other people as well as the fact that I worked at Fairview State Hospital when I was going to college and I used to take groups of people with autism and other developmental disabilities attitude to community and this is 30 years ago. Yes, I did this when I was 5. This is 30 years ago when people, you didn’t see people out in the community like you know adults with autism or developmental disabilities. And so people used to stare at us all the time.

So the point is that really it’s how you react and act to having this autism that make other people feel comfortable or not around you. So for example, I remember when Jeremy was small and I would take him out in public, and I had to teach him early on not to touch other things and other people because he loves bright letters and glittery things and so people’s sweatshirts and handbags, and all those kinds of things on them. So the point is I soon developed a sense of humor and so that when Jeremy would do something embarrassing like touch somebody’s purse, okay, which is kind of safe here in San Diego because people are really relaxed, but I know if I were in New York, they’d probably shoot at me, you know, they’ll turn around and get worried about Jeremy and touching them. And I would make a joke, you know, about how oh you know, I told him only go for the good purses, or something, and kind of break the ice of people with laugh. And then I did more humor about things than taking it so seriously. And I made the people feel comfortable about the fact that something different was happening or that Jeremy was not acting like everybody else. And so then people were more accepting of it and it kind of made them feel more comfortable around us. So if we feel uncomfortable with our kids in public, the public will feel uncomfortable with us.

And everyone remembers Christopher Reeves who unfortunately passed away a few years ago, but Superman who then became, I think he was the quadriplegic and he was stuck in a wheelchair. And he said, “I refuse to allow a disability to determine how I live my life.” And regardless of whether you believe autism to be a disability or not, if you have needs that are
not being met or your child has needs that are not being met and they can’t do everything that all the other kids can do, right now, then that is a disability. But you don’t have to make that determine how you’re going to live your life. You can choose to do so or you can choose not to do so, and I guess I’ve made, I’ve allowed the disability to determine how I live my life because I’ve kind of got back into the world of disability in terms of my career which before I did not. You know, I had worked with people in the state hospital and then I had moved to France and I worked in TV and film, and then I got back into the autism fields. But I didn’t allow my son’s autism to tell me how I was going to live my life. So I’ve had to do certain things and curtail certain activities. But I love to travel so either Jeremy learn to travel with me and I taught him how to travel with me or I travel without him. But I was still going to do the things that I wanted to do.

The whole problem though that I think all of us face is money because everything is so expensive when you have a kid with a disability. But you know, so you can’t do as much as you wanted to do before and two income family soon become one income families and I know that’s real but you try not to allow the disability to determine how you’re going to live your life and how Jeremy’s going to live his life. As far as I’m concerned, he has the right to a life like anybody else. You know, if they’re going to take supportive living out as an option in state of California, they’re going to have a big fight on their hands because Jeremy since he was little, has decided he wants to live in an apartment with other people. He doesn’t want to live in an institution and he doesn’t want to live in a group home. And so that is his right. That’s a civil right and so it’s going to be a huge fight now probably but I’m not going to allow the fact that he has autism determine how he ends up living his life. I guess I had that stubborn gene, the French stubborn gene from my parents. And I hope some of you have it too.

So what does that mean in a way? It means that we reexamine our personal beliefs in terms of disability and illness, okay, how you really feel about disability. See with me, when I had Jeremy, I’ve already worked with people with the disability, a developmental disability. And so I mean yeah, it was a big shock. I didn’t want that in my house. But I had an understanding of what it was and what it was like and I still had this respect for those people so it wasn’t something I was unfamiliar with.

And then the thing in our culture now is the striving for perfection, even neuro-typical kids, you know, it’s not good enough that they are neuro-typical but it has to be perfect. And we have to re-examine how we feel about that, and I think as a culture, we need to do that.

We need to compare our positive attributes maybe and not, in other words, not to compare one child to another, but maybe to focus on the positive attributes that our children has. And so you may be comparing in some ways, but you can’t compare in the sense of this is what
this child is doing and this is what another child is doing, because you know what, even neuro-typical children don’t do the same thing. And when I think about it, Rebecca, who is neuro-typical, she’s a great kid but you know, I know other people who have kids, no matter how great parents they were, the kids ended up doing bad things and making bad choices in their lives. Well you know what, sometimes it’s better to have a Jeremy who is a sweet kid, who is never going to hurt anybody well intentionally, than to have someone who goes out and becomes a mass murderer or a rapist, you know, or a drug dealer. So you know, that’s a positive aspect to think about with your child.

And again, you need to learn to focus on the similarities and not the differences that exist between the kids, and that’s kind of what we’ve had to do at home with Rebecca and Jeremy. If we always focus on what was different, then it would not be such a good thing.

So who moved my cheese? You know what, I’m going to go over here to see if there’s anybody trying to ask a question. I’m going to see who is on the phone first and then someone writes in, are the slides to be vastly a part of the grief cycle. Okay, great, so I guess I’m not doing the right thing with the slides here. So now, I’m going to try something different and you tell me if it’s working. Now is that moving better for you? Well, I guess that Ernest Priestly, the wonderful founder of momsfightingautism.com will really believe that I’m not good at technical details. Okay, because I couldn’t move my own slides, how about that. I can talk and I can walk but I can’t move the slides at the same time.

So here is where we are. I’m really sorry, and you know what, if you want copies of the slides, I’m happy to send them to you, you could email me or you can contact Ernest Priestly at momsfightingautism.com. You can email me on AutismCollege.com, if you go to that website. I’m really sorry to have messed up.

Okay, so we’re on this slide and I’m going to go now to answer some questions. I’m going to see is if someone is on the phone who wants to, if you do a *2, you can raise your hands. Okay, so I’m going to go to the written questions, then I’ll come back here later. Okay, does everyone see the slides now? Am I moving them correctly? Okay, I’m really sorry. I hope you all forgive me. Okay.

Hey Mark. Mark is on from Florida. Mark is one of Jeremy’s former tutors. Hope you’re doing well out there Mark. Here is, mostly people are just commenting about being on here. So here’s a comment though from Cindy. “My daughter has anxiety and OCDs trigger my anxiety disorder. I take anti-anxiety meds myself and the side effect of that caused me to become fatigued.”

You know, this is a really good example of our child’s autism affects us physically, and that’s
one thing that we really need to do is to take care of ourselves and I know it’s really hard to say, but gosh, is there another way to handle the anti-anxiety, perhaps speaking to somebody, learning some meditation, some breathing, different times of aspects so that for your health. I know it’s so much easier. I know sometimes I feel like now I’m drinking one more glass of wine than I used to in the past in the evening, and you know, because everything is so much more stressful but, really, I found that exercise is really great for helping to handle the anxiety. You also sleep better when you exercise. I can’t get out of my house very often because of all the works that I have to do, being a writer, I’m stuck at my whole office and also because I don’t always have coverage for Jeremy. So I finally bought down an elliptical machine so I can exercise and I forced myself to instead of sitting on the couch to watch show, I sit on my elliptical machine and do a few miles before I’m allowed to go sit on the couch. And I have to do my own rulemakings myself. So I don’t know if any of that is helpful to you.

I didn’t explain who moves my cheese. So adapting to change. Who moves my cheese is the story of this 3 or 4 mice who are stuck in a maze. Okay, and they are trying to find the cheese that they normally eat. And so they go to the part of the maze where their cheese normally is and the cheese is not there. So it’s the story about, I think there’s only 3 of them, but what happens to these 3 mice, one of them keeps going back to the same place where the cheese was before. And he ends up starving to death because he never finds the cheese. Another one keeps running into different walls and gave up because he can’t find his way to the cheese. And the third mouse ends up thinking okay, if I want to survive, I’m going to have to find that cheese. The cheese isn’t here, I’m going to have to look for it. And so he goes through the maze until he finds his cheese. It’s a work, it’s effort, but in the end, he had to adapt to the change that the cheese was not in the place where it normally was. Because if you just keep doing the same things over and over, well that’s kind of like insanity, you know.

How many of us sit here on our computer sometimes and something’s going wrong and we just keep pressing the same thing over and over and over hoping that what happens is going to change. You know, sometimes by chance it’s us and we have never figured that out, right? But it’s actually because you’ve actually done something different without thinking about it. But if you think about, this is different, so I can’t do the same thing I did before, then it’s going to be much more helpful then just doing the same thing over and over. So it’s adapting to the change in having the child with autism. Now, you have to learn about special education, it’s not the same as real education. You know, real education, you like that, right? That’s not the nice thing to say, but it’s sort of like saying normal versus neuro-typical. The point is it’s a whole different system and you have to adapt to the change of having somebody new, something new in your life. You can’t just follow the old rules.
The price of success is much lower than the price of failure. And what I mean by that is that because you need to be thinking about failure, the risk of failure. When you try things out, you risk failing. So sometimes, we are afraid to try things out because if we say, well gosh, if we fail, if we try and this doesn’t work, we’re going to fail. But you need to think about what would happen if you never took a chance.

So for example, if you’re in an IEP meetings and you really want something that you think your child should have, that the assessment show would be beneficial to your child so you do have a case. You have an argument but you’re afraid. You were afraid of attempting to ask for these things or putting together the logical argument and you say, well maybe it’s not worth it because I’m going to fail anyway.

Well, actually if you add up all the failures that you have because you’re afraid to do anything, that in the end is going to create more problems in your life. And so the price of failure is actually more expensive. It’s going to cost you more grief in the long run than the price of success. And you may have to put yourself on line more and more if you get success in certain areas. But it’s worth the cost because if you don’t try, you’ll never get anything and then you will feel failure, you will feel defeated. And that’s something that stays with you a lot longer and that will keep you up at night and makes you anxious, not the price of success, but actually the failures that we have when we are afraid to try things. And so really, it’s worth taking those chances and that’s why we do risk-taking.

There are risks in taking no risk and an example of that is I once met this motivational speaker. I heard him speak and he was a high diver. So he’s someone who goes way up way high on the highest diving platform and he can dive into a very small pool of water. So he used to go around the country and he would get paid for doing this at carnivals or at events, you know, openings of major malls, things like that. And the point is that he would have to go up on the top of the ladder and he would have to decide whether or not he could dive because there’s all these factors that come into play, like is it windy, what is the wind like because if he dives a certain way and the wind moves a certain way and they don’t have the pool in the right place, he could dive into the parking lot instead of into the pool. So the point is though that people have paid him to dive. So he goes up this ladder and you see hundreds of people around, well he has decided it’s worth taking the risk of diving or not if there’s wind out there. And you know what, sometimes there is a risk in taking no risk. So he takes the risk every time he dives but he also has to sometimes be open to not taking that risk and just coming back down the ladder which is embarrassing. But you have to do that and so risk-taking is always about evaluating what the results are. And for him it could be death and so of course, it’s worth coming back down that ladder and not taking the risk of diving. But other than something being sort of death or maiming you, it’s worth taking risks.
And that’s the same thing. If you’re afraid to ask for something for your child, if you’re afraid of pissing somebody off because of your belief, well you know those are risks and it’s worth taking those risks if it’s going to make you uncomfortable your whole life and feel like the failure that you don’t take certain risks.

And you always have to overcome the fear factor. What would you do if you weren’t afraid? And you know, I find it so much easier to take risks and to overcome the fear factor when it’s things that have to do with system and less with the emotion. So for example, when it comes to fighting for Jeremy, I can overcome all those fears pretty easily. It took me many years to do that, but I learn to do that by amassing all the possible information for my arguments with people. But when it comes to my emotions like things at home or in relationships with people, I find that a lot harder because sometimes, they’re afraid to have certain conversations with people because you’re not basing them on facts, you’re basing them on your feelings and your emotions and that’s a little bit different.

You have to know to pick your battles too. And when your kids are little, everything is you pick all the battles because you’re thinking this could be thing to save my son, you know, or my daughter and this is the thing that’s going to help. And you think that you’re just going for a quick short run, but it’s not. It’s a long distance run what we have. It’s a marathon. So as your kid gets older, you learn to pick the battles, because you know what, there’s no way I will survive for Jeremy reaching his age 22 if I was continually to take every single battle or every single thing that I felt would make a difference in his life, I’ve learned to pick over time, what are the things that are really worth fighting for and what are the things that are not worth fighting for.

Overcoming the fear of rejections, that’s a biggie because often we like to ask for things that we know that we’re going to have, that we already know it’s a done deal. But sometimes, you just have to be able to face the fear of rejection and realize that you will be turned down. Well so what, so you’re turned down, you’re rejected, you can try again another time. It’s like trying out for a job. It’s really harder these days now for people who are unemployed, but you know what, you only need one person to say yes. So you can go on a hundred interviews but you just need that one yes. So if you don’t put yourself out there for the 99 rejections, you’re never going to get that one yes?

And learning to say “No.” That’s a really tough one especially for those of us like me who think oh wow, that’s a great idea. Everything that I get asked to do, like helping with this conference is a great idea and I’m learning to say no. Obviously, I didn’t say no to this conference because I love the fact that there’s 2 days of information going out that’s free. So to me, that’s a no-brainer. But there are people in classes that are constantly asking for help and you have to learn after a while to say no, because otherwise, you’ll never have time for...
yourself and you’ll never be able to stay healthy, which is the next thing.

Take time for yourself. You need to engage in self-care. Health is worth more than learning. You know what, you can learn a lot easier than you can repair broken health. Well, it depends on why your health is broken. But seriously, you only have a little bit of health so it’s important to keep, you only have one body, so you want to make sure you keep your health as up as you can.

Okay, now I’m supposed to have more slides after this. I’m hoping they’re here somewhere. Let’s see. I’m just checking if there is a part 2. I don’t see a part 2. Okay. At any rate, I only have a few more slides and I’ll be mentioning them to you here.

So health is worth more than learning so eat right, sleep right, exercise. Then the negative influences that is really important. When you have people around you that very negative, you have to learn to kind of curtail that so keep more time for yourself and less time listening to the negative people.

Keep a sense of humor. Actually, we always need to have a sense of humor. If you don’t laugh about things, you won’t to able to survive because everything is just so difficult. So you have to be able to see the quirky side of things.

You need to take time out for yourself, and I know we don’t know all have time to be running out, running marathon. We don’t all have time to go play hours of golf. We don’t have time to even get our hair done half the time or get our nails done. So what can you do? If you can’t leave the house, you can still do little pauses that refresh so even if it’s not exercise. If you lock yourself in your bedroom and you watch half an hour of a stupid show, you know, like nowadays, I don’t even want to see a movie unless it’s funny. I want to see comedies, that’s it. If it’s not funny, I’m not watching it. The news, I’ll read it in the paper, I’ll read it online, but I’m not watching news footage, it’s too depressing. We have enough to deal with. You need your energy for the positive things.

So take those little pauses that refresh. Have that little cup of tea, take your 5 minutes to yourself. You know, as long as the windows are bolted, the doors are locked, your child is safe. So lock yourself in your room. You got to do that to yourself if you don’t have respite.

The last point that I wanted to make has to do with common sense about getting things done so you have peace of mind. It’s really hard to think about, you know, when we go to bed at night, a lot of us have a hard time sleeping because we’re always thinking about the things that need to get done. You know, like we focus on what we didn’t get done today. Well, the point is that it’s not about what we did not get done today, it’s about what did we get done.
And so when you go to bed, you should be thinking, wow, I’m really thrilled about all the things I got done today. What I suggest to people to do before dinner, write down the to-do list for the next day, all the things you didn’t get done that you know you have to do. And then, after dinner, you can reflect on the things you did get done and you’ll have more peace of mind, you’ll sleep better. But getting things done is really hard and so what we can do for ourselves and here’s the quote I have here is, “In absence of clearly defined goals, we become strangely loyal to performing daily acts of trivia.”

What this means is you know how we have goals on IEPs for our children. We need goals for ourselves and you can use ABA, applied behavior analysis, on yourself which means that you write down the goal. Let’s say you have a goal to get more information about supported living, that’s an example for me right now. So what’s the goal? To find everything I can and I think that Jeremy and supported living. So then I do a task analysis of what is important to do to reach my goals of getting Jeremy in supported living. Well, the first thing is I have to find out what the laws are, what his rights are. Secondly is what agencies would be supporting Jeremy, what is process for doing that, how does a certain agency helps. So these are all the steps I need to do in order to reach my goal. Then every time you take a small step, you can reward yourself with something.

And then another thing that’s really good to do is to find someone to be accountable to and to brainstorm with to help you find your goal, to reach your goals. And so for example, in the example I gave, I know a few people here in the San Diego area who works in this area, and so I could contact them and get information but I can also pick one of them to say, “Okay, here are the steps I need to do and so how do you think that I can do this the best?” And then you know, you know they’re going to check up and say was that information good that I gave you and you’re going to have to be accountable to them on whether you followed up on the information they gave you.

So when we’re thinking about now, we’re also thinking about the future. And tomorrow is about adventures in an uncertain world because you don’t know what’s going to happen tomorrow. But one thing that is really important is to be a part of the change that you want to see in the world. So for example, it’s very rough in adult services. Okay, and I can’t change everything for everyone but I hope that by doing my part with Jeremy, it’s going to be changing things for him and it’s going to be changing for other people. And I also hope that on this journey of finding Jeremy’s adult life, I’m connecting with other parents so that together, we are creating solution. So by that process, we will be part of the change that you want to see. We’re not just going to accept the status quo. So by connecting and creating with other families and finding others with the same needs and dreams, and sharing resources and time, you can create change in the world and we can look out there and create common long-term goals with people that are like-minded.
So in conclusion before I go to other questions, I’d like to end with saying that nothing can bring you peace but peace to yourself. Actually, “Nothing can bring you peace but yourself.” That’s Ralph Waldo Emerson. “Nothing can bring you peace but yourself.”

And I would like, if people could email me, I would be happy to send them copies of the slides. I’m really embarrassed as to why the other parts of the slides aren’t up here.

So here are some questions. Karen from Ohio wants me to repeat the quote, we clearly define goals and acts of trivia. I’m going to find that for you right now. I don’t know who the author is of this quote but it’s, “In absence of clearly defined goals, we become strangely loyal to performing daily acts of trivia.” And I have a good example of that just from my work which is I’m working on the book. My manuscript is due in August. Well I have to outline for myself everyday that I’m going to do 2 hours of either research or writing and I have specific areas that I’m working on in the book. Every day, I wake up at 5 o’clock and do that for 2 hours before I get Jeremy out for the day. And if I don’t have a schedule for myself like that or I don’t have goals for what needs to be done for that book, it’s nothing gets done because what do you do when you get up? You turn on your computer. And what do you do? Oh you check your Facebook. Oh I’ve got like 4 email accounts now, right? So I’m checking that. Then you’re checking your Twitter. Then you’re checking your LinkedIn. You’re checking everything and 2 hours have gone by and you’ve done nothing. You’ve done acts of trivia because you could just check once a day at the end of the day and you could be done with it. Okay.

Now, here’s a question from Marie. “How do you stay motivated?” This is Marie in Houston. “How do you stay motivated and not burn out when it comes to finding and implementing the various therapies that can be added every 3 months? After doing it for years and having 2 other neuro-typical children, it becomes exhausting and then the guilt sets in.”

Okay, well my first thought is you’re doing the best you can so immediately, get rid of the guilt. Okay. There is no room for guilt in our lives. Guilt is not a good thing anyway. So you have to work on not feeling guilty. You have to, at the end of the day, tell yourself that you’ve done the best that you could under the circumstances. And it does become exhausting. And so finding and implementing the various therapies, the thing is when your child is younger, you’re trying everything. But as they get older, you really have to just pick what you think is going to be the most helpful. I know like Jeremy is 22 and there’s a lot more available now than when he was little. And I speak at a lot of conferences. And when I’m there, I’m listening to other people, and I do feel, oh my gosh, maybe I should be trying this diet, or maybe I should be trying this therapy, or maybe I should be trying this. And I realize, you know, maybe I could be, but over the years what I’ve done is just try to figure
out what makes sense for Jeremy. Which therapies make sense for Jeremy and just try some of them. You can’t do everything all at once.

And what’s really important also is your child’s relationship with the 2 other children. And sometimes, that goes by the wayside. I wish now that I hadn’t spent so much time with Jeremy focused on ABA for 2 years where Rebecca wasn’t that big a part of it, you know, because she was a lot younger than he was. And so you realize that what’s so important though is including, is getting that family unit together, and doing things with the other kids. Therapy is important but it’s really the time that you spent with the other children. And please, whatever you can do, do not feel guilty, because you do the best that you can. Okay.

This is from Jane. “I have a 5-yearold with severe autism. I’m constantly challenged by the feeling of defeat which turns to complacency. I get short burst of motivation and then I burn out and those efforts are lost. I am frustrated with myself and feel like I do not do what I should be doing for my son. Do you have any advice?”

First of all, you’re a great parent. Do not beat up yourself. Again, get rid of that guilt feeling and the frustration feeling because you are doing the best that you can. It’s not easy having a child with severe autism. And I understand about being challenged with the feeling of defeat and then you don’t want to do anything. That’s kind of sometimes how I feel because it is so much energy that you use. The important thing to do is to allow yourself to have those moments when you do nothing like sitting down and just watching TV for a couple of hours instead of doing something you should be doing. But then you know that that’s going to give you the timeout that you need to do something at another time.

Motivation, getting those short bursts of motivation, then burning out, meaning those efforts are lost. Well, maybe the efforts aren’t lost but you have to think, well, what is it that I’m doing that’s taking so much of my energy? So you try and spread out your energy more so you don’t get just the short burst because it’s true that it takes time, it’s over time. As I’ve said, it’s not a long distance run. I mean it is a long distance run. It’s not a short distance run. So what you need to do is not packing so much and when you get those short bursts of motivation, what is it that’s giving you the motivation?

And I think that the burnout might be that perhaps, you don’t see right away an effect in your son or a change in your son from your efforts. Well the problem is that, especially with severe autism, you’re not going to see change right away and sometimes, I wouldn’t see change for the longest time for Jeremy, but you can’t give up and you can’t stop one thing and start another one right away. You have to be able to keep things going, so you have to do less to keep it going. Whatever it is that’s going to works the best.
So for example, with Jeremy, when we taught him the typing, I only worked with him half an hour a day. The person, Soma, who taught us, she said, just do have an hour a day as long as it’s a good half hour. And you know what, it took 3 years but he learns how to communicate that way, and you know, it’s still constant work. But it’s really important to stay with yourself and make sure that one way of feeling to see more about your child’s progress is to videotape once in a while. The other thing is people who come into house who haven’t seen your child in a while because they’re going to go, wow, I can’t believe he’s doing this now. Or he wasn’t doing this 3 months ago. And that is something that as a parent, everyday, when you’re looking, you don’t see.

Okay. Sylvia in New York City says, “My son is autistic and he is 17. He’s nonverbal. How can I help him start using a communication device to communicate with others? Can you give me a suggestion? He has good receptive language.”

Well I don’t know if you looked at Soma’s website HALO, Helping Autism Through Learning and Outreach. Soma devised a rapid prompting method which is a way of teaching typing. But if you learn her method, if you look online there for some ideas for your child to start pointing to letters and then learning to type, that’s one way of doing it. And the other thing is if your child is in the school system, you can ask for an assistive technology assessment. Okay.

So, this is from Deborah in North Carolina. “I am a single divorce parent of a 19-year-old daughter with ASD. We both suffer from abandonment issues. Her father left when she was 10. My dad, her grandfather, passed 4 years ago, and my brother and nephew had disowned us as a family since the passing of my dad. My daughter is suffering from all this abandonment from families. What I can do to make her understand that we cannot make family one to like or being in contact with us?”

You know, that’s a really good point. I’ve had kind of the same issue, not in terms of family but even with tutors that have become very close to the family. There are many that keep in touch over the years and there’s always 1 or 2 teachers maybe at school or tutors that you just don’t keep up with because of everyone’s like being so busy. And that’s been really hard for Jeremy because Jeremy always feels that as abandonment, because to him, that is his family. If he sees someone every single day and that’s the person he communicates with, he doesn’t have all the other stuff that we had. And I think it’s just gradually over time that they learn that you choose the people and they choose you and by making connections with other people who will be around is how you’re going to be able to teach her that. There are some things you have no control over and it’s not a good fun thing to teach but you will have to teach her that and you will have to teach her the positive aspects of making the contacts and connections with people that you do like. Sometimes, those are much stronger than your
family contacts.

And that’s all the time that we have for questions for today. I’m just going to clarify, Soma, if you could, because someone wrote in and asked about that. I’m sorry I didn’t get to all the questions. You can put in Soma, S-O-M-A, and HALO, H-A-L-O, and otherwise, you can put the rapid prompting method. Just Google the rapid prompting method and you will find information on Soma and on the rapid prompting method.

So again, if you wish to contact me, go to AutismCollege.com, AutismCollege all one word dot com. Let’s see if I can get the slide up here for you again. And you can email me any questions I have not been able to answer. And also you can find out information about any other courses coming up.

Thank you so much and sorry about the slides. If you have any questions that I was not able to answer, please email me and I will answer them online by sending you an email. Thank you so much. Enjoy the rest of the day and BE THE CHANGE THAT YOU WANT TO SEE.

Thank you.

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