A New Look at Adults and Teens on the Spectrum

Michael John Carley

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**A New Look at the Needs of Adults and Teens on the Autism Spectrum**

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*Guest Speaker: Michael John Carley*

Chantal  
Good evening and welcome to Moms Fighting Autism, tele-seminar. I’m your moderator Chantal Sicile-Kira. I’m the author of three books, the latest one being, *Autism Life Skills* - from Communication and Safety to Self Esteem and more. *10 Essential Abilities Every Child Needs and Deserves to Learn* and I’m also a parent of one neurotypical teenager and a 20 year old guy in crisis, quite severely with autism. And I’m happy to be here this evening to introduce our guest this evening, who is Michael John Carley. I’ve known Michael John Carley for a few years now. I’ve had the pleasure of knowing him and I’m going to tell you a little about him before he gets you more information as well. So, Michael John Carley is Executive Director of GRASP, which is the largest organization comprised of results on the spectrum. He is an accomplished author and speaker. Michael received his BA from Hampshire College in 1986 and his M.F.A. from Columbia University in 1989. As Executive Director of GRASP, he has spoken at conferences, hospitals, universities, and healthcare organizations. He has appeared in the media widely, most notably, the New York Times, the Washington Post, New York Newsday, the London Times, the Chronicle of Philanthropy, the Chronicle of Higher Education, Newsweek on Air, ABC News, Psychology Today and so on. He has also been on the radio, on NPR, on Terry Gross’ Fresh Air, as well as the Infinite Mind. Carley was featured in the documentary on the spectrum and the soon to be released documentary, *Neurotypical: The Movie*. His article, *Grasp at One Year, A Personal and Unprofessional Look Back* was widely circulated and his other articles have been published in magazines, such as Autism Spectrum Quarterly and newsletter, the OARacle. His first book, *Asperger’s From The Inside Out: A Supporting Practical Guide For Anyone Asperger’s Syndrome* will be released in April 2008. Until 2001, Mr. Carley was the United Nations Representative for Veterans For Peace, Inc. In that time he was known primarily for his work in Bosnia and in Iraq as the Project Director of internationally acclaimed, *Iraq Water Project*. Prior to 2001, he was a playwright who enjoyed 15 productions and 10 readings of his plays in New York. Along with his (then) four-year old son, he was diagnosed with Asperger Syndrome in November 2000. He lives with his wife Kathryn Herzog and two sons in Brooklyn. Welcome Michael, you’re a very accomplished person.

Michael  
Chantal, you can say that or you can say, why didn’t anything stick?

Chantal  
Well, you know what, I see you as a Renaissance Man.

Michael  
That’s the good way of spinning it. And we always go with the good way of spinning it.

Chantal  
Well, you’re going to be speaking to us about a new look at the needs of adults and teens on the autism spectrum. Obstacles and the myths surrounding capabilities. As well as answering questions that people have been e-mailing in. But, first would you like in your own words after I’ve given that description and managing to mispronounce some of the words that I spoke. Would you like to tell a little about yourself and explain to people more about what I just described you as?

Michael  
Well, I’ll just sort of add just a couple of things on each, on each segment. The first having to do with GRASP, the organization that I get the great privilege to be able to run. Grasp does a
lot of thing, but really its bread and butter are its regional support groups that have to be run by someone of the spectrum. Now obviously, that person has to be, you know, capable of certain things, has to be willing as well as able. We do a lot of other things though. Educational outreach, we, you know, had to drop-off the advocacy work a little bit of late, but the real main thrust are indeed those regional support groups where folks on the spectrum at any level, you know, come into meetings and instead of support group meetings that are run by doctors and clinicians, like Rouke use to. They suddenly, they can sometimes feel a little more thrust because the person up there, you know, has that same juice as them; even if it’s to a very, very different degree. Most of the time, if you’re an individual on the spectrum, you’ve grown up trying to explain who you are to the rest of the world and you know, a lot of times it doesn’t work out. And just like any of us, you get to a pints where you say, you know what I quit and you internalize more. And suddenly you have this opportunity now with somebody up there that might actually get you to a degree that, you know, that you’re thinking maybe I can trust this person more and expose more of myself and so. Now that having been said the whole peer, run support group model is no something that we’ve invented by any means. It’s a concept that worked for returning war veterans, it’s a concept that worked for breast cancer survivors. It was, just probably not thought of as something that you would apply to the autism spectrum because of the communication issues having to do with the particular diagnoses. But we’ve had a very, very good run of it and we’re very quickly. We had originally planned going national in our seventh year. And not because we were doing anything brilliantly administratively, we went national in our second year and it was because we had a great need and people were really, really ready for something like this. I guess, the only thing on a personal level that I would add is that I, when my (then) two-year old son was starting to get looked at, for a lot of the things, that I’m sure a lot of the people on the line are very familiar with, speech delays, motor skills issues and he was stacking the bulk dog food that we would buy into these unbelievable shapes and patterns. He also wouldn’t really play with toys, he would separate them in piles determined by shape or by color and, you know, you give him a toy truck and he spins the wheels to see how the wheels moved opposed to actually “playing” with the truck. And I never heard the word - Asperger's Syndrome - before and it came into our minds as a very, very possible solution for, at the time, our only son, whom we call Cee Cee for public reasons. And when clinicians are starting to key in on the kid, they’re also, because of the genetic nature of all of this, are starting to look at dear old daddy out of the corner of their eyes, a lot of the time and one thing led to another and he and I were diagnosed exactly a week apart in November 2000 and that’s kinder how I came into all of this.

Chantal Well, very interesting. Now, I would like to have your talk a little bit about your book before I starting asking you some questions.

Michael Sure

Chantal Such as those that people e-mailed in, only because I find your Asperger's From The Inside Out to be very interesting book. Can you explain why you decided to write that book?

Michael Well, there really was no information. Right now, you are experiencing across this entire country, adults that because of the expanding diagnosis, because of all the new public information that’s circulating and because just that type of knowledge tends to spread, it doesn’t really get dumped on a population all at once. You know, you start out at some epicenter, you know we like to think we’re in New York City, that we’re the epicenter of everything and it generally trickles down everywhere and what’s happening right now is that adults are being diagnosed in retrospect, in absolute droves, such as myself, although at the time, I of course thought that what I was going through was something that nobody on the planet could possibly also be going through. And when, you know, you know, I find out that there are truckloads of people going through the very process. And there really was no
book for them. There was no book that charted, chronologically, what you go through on an internal level about things like what does this mean to your identity: About, ok now that we’ve figured out exactly what we’ve got, we can: A - stop pretending that the way that other people might fix their problems in life might not apply to us exactly. That there are exactly, now that we know this about ourselves, other ways that we can try, that have been somewhat proven. So it’s sort of like, you know, the figurative example that you that the wrong toolbox to change the things in your life that you wanted to change. Now you finally have the right toolbox because you finally have the right information. And there’s also a lot internally, you know, as to what goes on, you know, maybe, you know, you’re somebody that grew up with ideas about anybody with a “disability”, that you know left you thinking that people like that were just broken and there wasn’t nothing you could do about it. That’s going to make things harder if you had an upbringing like that. Here’s what you’re going to go through. And, this no small task because an adult going through this diagnosis, you know, gets near biblical how almost every event that possibly happened in your life prior, suddenly gets reexamined in this new light and you come up with very different assessments and conclusions. You come up with, you know, people that you though were really awful to you then you find out that maybe they were actually trying to challenge me. And maybe there are people that you felt were heroes in your life and you look back and that they weren’t being very heroic at all now that I think about this twice. You know, the point being, everything changes with this and that’s a good thing, not a bad thing. So to have some sort of a road map for people to get some idea of what they were facing with this late diagnosis was something that was just not out there. And I, you know, Tony Attwood has diagnosed more adults that anyone, but I’ve probably seen more adults after the diagnosis than anybody on the planet, so you know it was a book that I certainly had in me and it was proven in the writing process. It really wasn’t a struggle; it just kind of spewed out and you know, it was just one born from professional experience, as well as personal.

Chantal Now, when I’ve heard you speak before; interview you in the situations such as, on my radio show, you’ve always spoken about the moment when you received your diagnosis as providing you with relief, a sense of relief with the emotion that you felt. Did you want to speak a little more about that?

Michael Sure, I mean it was, it was. There were two overwhelming positives and two very small negatives to receiving the diagnosis and the two small negatives; one was that, I had had a sense somewhere inside me, all my life and I was thirty-six when I was diagnosed, just to give people a frame of reference. I had had this sense that I was not connecting at all on an intrinsic or karmic or whatever level you want to call it with the people in my life that I loved very dearly and that loved me very dearly. But you brush feelings like that aside, you go, no way can that be true, we love each other, so we must be connecting right? And you just kind of sweep it under a rug for all those years. And I think one of the negatives was that this proved, proved that no, I wasn’t really connecting with them. And that was a little hard to take. What you to realize is that it doesn’t really interrupt the love that’s going on necessarily whatsoever, but in terms of what we think of is that you know, really big sense of shared experience, no that wasn’t happening. I was processing thought, I was processing emotions, I was processing experiences much differently that the people that I loved. And I think the other small negative was just that we do have real stigmas attached to these words like autism and Asperger syndrome. And I’m somebody that had had somewhat of a life, you know, my resume had some accomplishments on it and now, you know, most of my behavior differences and this where I was very, very lucky, is that most of my behavioral differences were lumped into the category of Artistic Eccentricity, based on the professions I found myself in. And so I go a free pass, where a lot of the other adults that I see certainly did not get a free pass and went through miserable, miserable experiences. So all eccentricities are suddenly not part of this really unique artistic personality of Michael John Carley. Now suddenly they’re just lumped in to the cold stigmatizing mark of a diagnosis and that’s hard. But the overwhelming
positive blew all of these negatives right out of the water very, very easily. The weight that was lifted off my shoulders was something that I’ll probably never be able to describe. Every banana peel on my resume, where I may be hurt somebody’s feelings; suddenly I realized I had not meant to hurt their feelings. I truly had not. And that, when people made the mistake by thinking that I had intended to hurt their and I had thought to myself, but I really didn’t, you still tend to go with the majority. If everybody around you is telling you that you intended to hurt feelings, then you start to believe it yourself. And this freed me to tell them that I was a much better person than maybe at times I had led, even myself, to believe. I had supporters you know, I was a rude so and so and this and that to my detractors and to my supporters, I was a “tell it like it is” guy. Everything made sense. All those experiences in life when you walked away scratching your head going “what the heck was all that about”. And now you know. And that’s just too beautiful to be conveyed over a phone interview.

Chantal I really appreciate you sharing that with us.

Michael My pleasure.

Chantal We’ll start with some questions now.

Michael Sure

Chantal Ok, so here’s one. The first one I’m going to ask you is from Lisa Perkins, from Caseyville. My thirteen year-old has great difficulty with social cues. I worry because he misinterprets them quite often. Any suggestions for therapy for him and where to do? He is currently seeing a psychologist. I’ve been unsuccessful in finding a social group. Any help would be greatly appreciated. Thank you.

Michael There’s one particular form of therapy which we like very much and that’s what’s called cognitive behavioral therapy. Also known as CBT. And the difference with cognitive behavioral therapy is that it really takes the patient into the process of becoming their own doctor. It really doesn’t have as much of a ‘you lie on the couch and do what I tell you’ versus, I sit in the chair and scribble notes and hold all the keys but don’t share them with you. Which can be a wonderful relationship. It worked for me for a couple of years at one point. But cognitive behavioral therapy really shares with the individual a lot about their own diagnosis. And the more the kids can start to understand about what they’ve go, is only going to help immeasurably because on their own, what they might be thinking is that, you know, I can take care of this, like other people take care of this. And that’s when a lot of mistakes start to happen. With cognitive behavioral therapy and with the whole notion of really learning about the diagnosis so that they also sometimes can start to alleviate the societal stigma that still accompanies these words. We just find that’s a wonderful, wonderful strategy in terms of psychiatric therapy. Now that having been said, all these great ideas, whether they’re therapies, you know, or having anything to do with policies or whatever, you know, this is all going to wind down to being about the singer and not the song. You know, and the wonderful practitioner that might be the better idea if the practice a less than ideal therapy versus the absolute jerkF that practices your ideal therapy.

Chantal Right. Do you have ideas for helping someone find a social group?

Michael Really, um, with finding a social group, finding a good school program, with finding a good therapist, it’s really all about contacting whatever local autism societies or local Grasp chapters, if you have one local, local agencies that really were non-profit, excuse me, that really deal specifically in the autism spectrum, is always going to help more than cold calling through the, through the white pages. You know, what you want is a reference. What you want a caller to do is to call people in the know. You want to get involved, you
want to get on all the parents support e-lists, you know, this is a situation where quantity is always better than quality if you, if you’re new to all this. So you just really want to absorb as much as you can because in a pinch there’s probably going to be someone from your area that has been through this before and knows the field a little better.

Chantal Now that’s really great advice because a the, whatever autism support groups that are around usually there’s a parent there that’s been through it all and it’s really good to find out what other professionals have been seen and what the opinion is and also for what social groups are helpful for which type of child.

Michael Right

Chantal You know, what type of personality the child has as well. And I’m going to give you the website, going to read the website right now for Grasp, its www.grasp.org

Michael What I would suggest to your listeners, the people on the phone, not your listeners, this isn’t radio, do is to subscribe through the subscribe button, there at the top and when you subscribe, when ya’ll subscribe, you’re going to select the families and clinicians list from the drop down menu. Don’t, if you live in Philadelphia and you see there’s a Philadelphia group, don’t hit Philadelphia because the regional groups are there for adults on the spectrum only, but what you want are the families and clinicians list and that will get you also to an online Yahoo group where you can converse with people all across the country. And it’s all free, so it’s a no brainer.

Chantal Alright. Okay here’s a question from Interested Mom in Albany. Hi Michael, I saw you speak in Albany, NY last year.

Michael Oh, hi Interested Mom. Nice to see you again.

Chantal You spoke of having a dog and how important that was to you as a child. I have an eight year-old and a six year-old on the spectrum. I’m wondering if I should get a dog, I have mixed feelings about it. The extra responsibility I would take on to have a dog and care for the correctly, is a big commitment, but at the same time, if you can tell me it helped you a great deal and it’s what helped you get through the day, I’m all for it. Can you give me more details about your personal feelings on the subject?

Michael Well, you’re absolutely right, Interested Mom. It is a big commitment and overall, I think pets in general, seem to have a really good, proven track record amongst folks out the spectrum. If they are indeed experiencing, you know, some sort of dislocation from the peers. The only thing I would, I would, you know, before saying yes, by all means, go out and get a dog; dogs are the best thing on the planet, is that I was a dog person and other people are cat people. You know, you, you have all these famous people on the spectrum that have these unnaturally large amounts of affection for certain types of animals. Author, Jerry Newport has something like thirty birds in his house. Leigh Ann Holiday Willy, who wrote Pretending to be Normal, she’s worked with horses all her life and now has a stable of her own and that’s her job now. Temple Grandin, probably the most famous one of all of us has revolutionized the cattle industry because of her, her work with cows. And we certainly know lots of, particularly women, on the spectrum, who love to have fifty cats in the house and I was a dog person so I guess it’s really, you know, finding out which pet is one that your children are really, really drawn to and if you find their more tend to dogs, then by all means, go get a dog. It’ll be great.

Chantal If I may say, because my son has a dog, and a really wanted a dog and so he has an assistant dog that is very well trained. But it’s true that when you have pets it is added responsibility, so that I think it’s very good that the Mom is thinking about that aspect.
Michael Absolutely

Chantal That’s not an added stress. What I would suggest too is to make sure that no matter what pet you have, that you start getting the children or if it’s just for one child, the one child involved in caring for the animal. Just starting in small ways. Because that way, it gives more of a connection between the animal and the child, and also after a while, the mother will feel less stress too because the child will begin to take on a little more responsibility. But in saying that, my neurotypical sixteen year old has two cats of which we end up feeding most of the time.

Michael Well, you know, I mean they bring pets into the rest homes now, you know, and it’s because it’s been clinically proven to reducing anxiety levels and reduce stress if you have a pet. Ah, I feel a little bit like a hypocrite in saying all this because, as of the last dog we died in 2004 and with a, two boys and we live in a fourth floor walk up, you know this is the first time in my life in which I find myself pet-less and I’m ok with that because two boys are enough responsibility, but I don’t really know, you know, I think there’s been some, ahh, idea every once in a while, you know, because of our diagnosis we have some strange star trek like, a kinetic relationship with animals, were we can connect with them on deeper levels and I don’t really buy into that. I think we know somewhere inside us when we’re young that’s it’s not really working out with our peers, as much as it would, with other people. We’re just going to put more of our energies into the animals.

Chantal Right, I see. Interesting. It’s true; animals are great, you know, they’re great for everyone I think.

Michael They’re great family members. Not just pets

Chantal Exactly, exactly. Ok, here’s a question from Deborah Pretzer from Fresno, CA. What are your survival successes from parents of the teen and for the teen to get through the, that stage, guess teenager stage, relatively smoothly?

Michael We’re veering off the autism road here.

Chantal I think both together can make a volatile mix.

Michael I certainly understand that. I think that, you know, the joke aside I mean, teens are really, if, if, if they’re developed mentally in line with their peers. What they’re trying to do is really separate themselves and break away. They’re starting the process of breaking away from mom and dad. And, this is difficult for any family. And I’m sort of unqualified to speak of this, as a, as a dad because the oldest is now twelve, although he’s really starting to give signals of, you know, that particular part of the separation. And, you know, I every once and awhile catch myself going, God, he’s getting me to overreact and he never did that before, you know. How is he doing these little magical tricks? So, I think just not taking personally some of those, you know, separation gestures of his are probably going to help enormously. And for a teen on the spectrum, it really depends on the kid. I don’t know where Debra’s, you know, child is developed mentally, or in terms of his executive functions abilities. And without that it’s a little hard for me to sort of, you know, evaluate where he’s at in line with other teens so that maybe we can start to. I mean, no matter what his body, you know, is doing the same thing as other teens. So hopefully some sort of sexuality curriculum, no matter where he is on the spectrum is, is out there for him. Both, you know, having to do with, you know, what’s going on with his body, as he goes through puberty later and also what’s appropriate and what’s not. I think that patience is probably just the best and not taking things personally is really the best suggestion for any teen, whether it’s on the spectrum or not.

Chantal And I think that a lot of times it’s important to remember that even just neurotypicals, when they hit those teenage years.
Michael: Yeah

Chantal: There are some things that go on that I think that when you have a child on the spectrum, it's kind of important to look at what, okay, what is a going to be happening because of puberty and usual teenage stuff and what is really due to the autism? And

Michael: Right

Chantal: He doesn’t generally have a lot of stuff going on.

Michael: I mean one of the things that is probably, that I should probably state right now that’s probably going to effect a lot of these questions is that a lot times I get jealous of people that deal with kids, especially young kids, because kids have this very fewer autism, Asperger syndrome, where the symptoms are there, they, you know, just match up with what the dsm and you just work with that. But as anybody gets older they start to have these things called life experiences. And then those life experiences that sometimes, you know, will hopefully, some of them are positive, but the ones that are negative can produce things like anger and anxiety and depression or non-chronic depression. Because if it were chronic, he would have been born with it. And it’s very, very, very helpful I find for everyone to really separate, what’s the actual diagnosis at work here and what’s that anger, anxiety and depression at work here, because the diagnosis obviously, you’re not going to do anything about. You can improve on certain things on a cognitive level and you know, various aspects of assimilation and getting by in the world, but the anger, anxiety and depression really at their root are not a part of the diagnosis. They’re just sometimes the inevitable by-product of having lived life in the behavioral minority and you know, any marginalized population or other minority knows it’s a lot harder when you’re in that position. So I think that you know, if, if the anger and anxiety and depression are sort of really, you know, screaming out loud “I need a little bit of help here” then you treat that more, you know, you treat that with the knowledge of the autism spectrum sort of, but you really after the anger, anxiety and depression.

Chantal: Good point. Here’s from Nancy Ricotta in Sterling Heights. Strategies for students in middle and high school to deal with bullies. Any advice?

Michael: Yeah, I guess lots, I mean number one, if you’re talking about just the student, which I don’t think you should do. I think that you know, ideas with bullying are a community wide problem. I think there are things to bolster an individuals. I think the walk away stuff doesn’t work. I think that a lot of success can be had by giving them certain empowering traits, shall we say, and for some people that might be yoga and for other people that might be boxing. And maybe trying to give somebody, at least you know the mirage that they have it in them to defend themselves. And that also might be, you know, treating some of the anxiety that they might be experiencing because of these particular situations. But I really think that if there’s a bullying situation, that the environment has to be addressed. Just as much as the child’s needs. You know, we know so much more about bullying now, then we did we I was a kid. And not only are we starting to hold, you know bystanders that do nothing, much more accountable, then we have in the past. The teachers, you know we found out were fairly, you know culpable problem at times, as well. You got this kid in the class, you know, especially in midstream schools, if you’ve got one kid on the spectrum, whether that kid knows it or not and the kid is who he is and, you know may inadvertently be indeed disrupting that teacher’s class, well that teacher, on a really subliminal level, if that kid becomes bullied outside of class, he’s not exactly going to be feeling all that critical towards the kids that are doing the bullying. He’s going to feel at least a little bit grateful, even if it’s on the most surreptitious levels, you know it’s that whole thing of, that kid had it coming to him, that some way sort of springs out of nowhere. But, no matter what you got to take the idea that this phrase
bullying is a part of life is, at the very least, absolute garbage. It’s a phrase that I find has
been perpetrated by mostly people that in their youth were the bullies themselves. They
seem to be the only ones who seem to throw that phrase around. And a lot of studies
exactly do show that those former bullies don’t fall down in gutters after three marriages
and a series of dead-end jobs and dead livers and you know, the last thought they have on
this earth, as they die of cirrhosis, is, “boy, I wish I hadn’t bullied poor Johnny back then,
you know”. It’s a great fantasy of everybody’s. Turns out that the bullies now get really
good jobs when they grow up. Turns out the bullies are thought of very highly in their
communities. And the individual that does get bullied usually grows up with minor
league versions of post traumatic distress disorder. And then feels doubly bad because he
hears that garbage phrase “bullying is just a part of growing up”, all the time. And so he
feels doubly worst because all these years later, he’s still hurts and so that phrase makes
him feel even worst; that he’s a complete loser for still feeling hurt all these years later.
So, bullying is not a part of growing up and unfortunately it’s just, it’s an absolutely
community wide problem in terms if you’re going to address it properly.

Chantal  Now, do you recommend that book, I think the author’s name is Nick Dubin?

Michael  Yes, Nick wrote a good book on bullying. As a matter of fact, there’s this guy named Michael
John Carley that wrote for the foreword for the book, so yes.

Chantal  Would you like to mention the name of the book?

Michael  You know, let me just check my library here. I’m at the office, so. I could never remember the
full title. We, in this industry, don’t write books with catchy titles, so they sometimes
need to be

Chantal  It’s Nick Dubin, D U B I N.


Chantal  I’m going to continue here Michael.

Michael  Go ahead

Chantal  If we get it wrong, we can mention it, but here’s another question from Nancy. Ways to
constructively combat school administrator’s desires to re-class students from General Ed
supported to ASD, when it’s against the wishes of the parents and doctors.

Michael  Well, kids have this thing called the IAP and it’s against. It can’t be against the wishes. If it’s
going against the IAP, then you can take them to court and sue them. So, this is on the
IAP and the school administration is going against the IAP, you need to get a lawyer.
Otherwise, that has to be a plan that you must have come up with yourself.

Chantal  Ok, Cecile Murdoch from Hanscom has this question. Or maybe her name is Cecile Murdoch
Hanscom?

Michael  No, it’s Hanscom Air Force Base, I think?

Chantal  Oh, ok. I’m sorry if I’m murdering people’s name. I have a double barreled name, so I just
assumed everybody is. The way these names are written on here, they’re (inaudible). Do
you know of any resources that help military families in particular? Our kids deal with so
much change. Just moving as much as we do and starting all over again each time. That
must be quite difficult.

Michael  You know, it might actually, I mean I’m not saying it isn’t difficult and I’m not saying that the kids
don’t rebel against it and aren’t hurt by it because we all know that you know, transitioning from one thing to another is very often a challenge for folks on the spectrum as is really any kind of change, you know, people on the spectrum like routine. Because it’s sort of a safety valve in the midst of you know, living in the universe you don’t really get some of the time and routines are things that we can count on. There is, not to sound like the jerk football coach here for a second, but I mean, there is a possibly that experiencing change and getting use to change in this particular manner, night actually help them long down the road, but you’re not going to see that in the short term. So I understand the concern of Miss Murdoch. There is nothing in particular for military families and this is really just an absolute travesty because usually in my experience, military bases where the families usually live are woefully underserved in terms of anything that has to come up, you know anything that comes up that’s out of the norm. You know, you’re going to have your grocery store. You’re going to have your pharmacies. All that sort of stuff. Anything specialized that needs, you know, kind of, more outside the box attention is usually something that military bases, in my experience, really shortchange. This is no special legislation. Somebody had talked about something being proposed awhile back, but I don’t think anything happened to it. It’s really a shame. So, you know, all I can say is Miss Murdoch, “it’s not fair and considering what you’re going through and what you’re sacrificing, it’s really kind of a crime.” And I apologize.

Chantal I may have a couple of suggestions, only because I lived in the San Diego area and we are very much a military town down here

Michael Yes, you are.

Chantal And so, I can’t, off of the top of my head, name any websites, but I do see in the San Diego area, where people have on certain of the support groups here, mention resources or families in the military. And so I would say, if you want to contact me and e-mail me, separately, I will find those and e-mail them along to you because I don’t know them off the top of my head. So that’s the first thing. If you Google my name, you’ll get my website and inside there you can contact me by e-mail. And the second thing I want to say, something I agree with Michael in that over the long term it can help the child, but it is very hard moving every three years at the beginning and what I would suggest is things that I have seen people do successfully just when they’re going away on vacation, or they’re changing or moving in general, is to have like a photo album showing what it looks like to have a move. You know, when a truck is coming to the house taking the things away and then you end up somewhere else. So maybe the first couple of times, the child will not really understand or still going to have a hard time figuring out what’s going to happen next, but after a while when it comes to the next move, they’re going to say, oh that’s going to be happening again. And then eventually, over time, anything new, you can be doing that, creating social stories, having stories about it. But pictures to begin with, if they seem to be in tune, if their visual processing is working. But that something that seems to be working with many people that I have spoken to, you know whether their child is on the more able end or the less able end of the spectrum. So I would kind of suggest that kind of thing.

Michael That’s a great suggestion. And I have one more is just that, and this is only if the child in question, or the children in question can process such an idea and not knowing where they fall on the spectrum necessarily, if it can be communicated, that because of the lives that has or the life that family has a collective, because of being in the military, if it can be communicated, that, that’s really what is expected, it’s not expected that we’re going to stay in one hometown until you graduate from high school. You know if you change the expectation of what is, what is the norm, it might kind of bring things back around. And if, if there can be this idea that, you know, that every couple or few years we move and if we don’t move, then something really freaky is happening, then you can freak out. Cause
then something would have happened that was so nice. Just getting the child or the children to understand to sort of understand the break in routine as being routine based on who they are and what their lives are all about.

Chantal Very good. Ok, so here’s another question from Erica Kirkland from Birmingham. My son is fifteen and has Asperger. He is high function. What can I do to help him better peer choices? He is so easily influenced and tends to only get accepted by the non-desirable peer groups.

Michael Well, kids can be kind of cruel and it may actually be, the less desirable peer groups, might actually be his best chance for learning social skills, if that’s the group that accepted him. Because you certainly won’t want your child in a peer environment where he’s disrespected or being made fun of all the time. I’ll share a little tidbit from my past, is that you can talk about all my degrees and semi lofty accomplishments, but that wasn’t what was really expected of me based on people that saw me when I was fourteen or thirteen years old and the ahh, the straight lace kids wouldn’t have anything to do with me. Too weird, too this, too that. And I grew up in Providence, RI, back at the time when Providence, RI was really just a mob run, economically devastated dump. And, some of the most notoriously juvenile delinquents running the streets in that city took me under their wing. Now, it was a situation where I never, you know, did any crimes with them. As a matter of fact, everyone would make fun of me for that fact. But it was, it was still a situation where they came to pick me up and go, you know have fun with them at night. And there was a lot of risk to this, you know there was, it was an atmosphere where there were some drugs, but I never those. I drank with them though. And, that was still going to be, not just the best chance at peer relations, but one that I really, really look back on an am eternally grateful for. Because I did at least have this sense in my mind and I’m not saying, you know, that your child in has this sense in her mind, but I know this was going to end sometime. I knew that things were going to probably improve and that I would be leaving these people in a figurative and literal way. And that thought running through it was just something that I felt a little guilty about because I did care about these people even if, you know, I kind of knew a lot of them had really bad endings to their life stories probably, at some point. But they taught me compassion and they taught that there are a lot of great secret inner beauties in lives that are looked down upon by the rest of society. And I could never deny that those years which I’m glad I got out of, don’t get me wrong, but those years, you know, have made me an infinitely a better person and that’s affected my work at every job I’ve ever had.

Chantal Here’s a question from Lori in Ohio. I find one of the hardest things for my son is to talk to peers, both male and female. And I’m not sure how to help. I’ve worked with his school and they don’t seem to do anything to help. Any ideas?

Michael Well, it really depends. The child might be having difficulty with small talk. There might be a lack of maturity, so the child doesn’t really know how to fit in and gets nervous and starts talking about something that might be inappropriate at the time. There’s also maybe the capacity whether or not this child actually wants to fit in. We’re going to assume that, you know, that he or she does but. There are plenty of children out there that just really don’t want to socially interact because they’re just not really that happy with their peers at that particular, you know juncture in time. I would say that there’s got to be some sort of a social skills class or group again if, you know, contacting through local office societies or local Grasp groups, or what have you. And then trying to find something that, you know, will possibly help with this. But if it’s something as small, you know, pragmatically understanding what small talk is all about, I think that this is a child especially that needs to know about their own diagnosis and that needs to really start, you know, begin to read books, you know like “Freaks, Geeks and Asperger’s Syndrome” that was written by a thirteen year old kid with Asperger’s, named Luke Jackson. To start to realize where these mishaps are happening in conversation with their peers. Kind of like, you know, if
kids on the spectrum walk a little funny and they know about their diagnosis and they’re not ashamed of it. Then, I just, I, well have somebody videotape how you look when you walk, you know, and compare it to the videotape of other people walking and then make the changes.

Chantal  Good. Here’s a great question from Terri Wooldridge from Baton Rouge

Michael Baton, Baton, you French person, you. (laughter). . . . If we, if we decide to bastardize your language, you’re just supposed to take it and lump it. Don’t you know that yet?

Chantal  Ok, don’t make fun of me, people are listening.

Michael  I’m not. I made fun of our country for having changed your language.

Chantal  Here’s a question. How can one be sure that their young adult with autism is ready to drive when nothing is 100% with them? That’s a great question.

Michael  Yeah, it is a great question. Although I must admit my immediate answer is I don’t know how you could be sure that any young adult with or without autism is ready to drive. You know, this is a completely new set of pressures that have very real consequences, very visible consequences and it’s a very, very scary idea, you know, make a mistake and get into a car crash. Whereas, you know make a mistake in a classroom and no big deal. I think that you probably just have to, if there’s some trepidation on Terri’s part regarding her child and Terri probably is on to something that might be a little more challenging for her child. And she’s probably right. So what I would suggest is to go slow, you know, don’t take the usual student driver classes before you go in for, you know, at whatever driving school you might have locally before you go in and take a driver’s test. You know, maybe double up on the lessons and let your teacher at the driving school know that, you know, that your kid, you know, through no fault of their own, that your kid is going to need a little more time and maybe space the lessons out and be as reassuring and as comforting as, you know, getting a good instructor is going to help enormously here too. You know if you had the guy I had, you know, it’s like do this and do that, ahh, you screwed up, is probably not going to work. So, I would say maybe investing in twice as much driving school as other kids as a start. And also you can help, you know, your child yourself probably, you know finding that empty parking lot and just taking him out there with your car and seeing, you know, how much anxiety there is when they’re in first gear and going five miles an hour and trying to work their way up.

Chantal  I think also a lot of making, a lot of self stories of examining how important it is and how serious it is with the driving. In fact, to be consistent, so more discussion about what the importance of, you know, if you make a mistake, as you were explaining in a car as more important or had more detrimental effect than making a mistake in a classroom.

Michael  Hmmmm hm. Hmmm hm.

Chantal  Ok, so here’s a interesting question. Mike from Levittown. My son is 17. He has a strong sexual urges and desires. How do you handle that? I don’t want to tell him it’s wrong, but I have to tell him something. He has had some exotic dreams then he says I can pee on so and so. I always tell him in a laughing voice, no you can’t pee on people. Then he asks me if he can lay on so and so. I always say no, but you lie next to someone if she’s your girlfriend when you get older. Is that wrong? How do you deal with this?

Michael  Umm. Well, I think it’s really health that this seventeen year old has strong sexual urges and desires just to start so. Obviously, there’s conversation going on about sex between Mike and his son, and that’s great. There’s no a lot of conversations sometimes between kids on the spectrum and either one of the parents because I think in past years we got into a
really bad habit about not giving kids on the spectrum the same attention for, you know, sexuality curriculums and you know, sex ed, as we call it. Based on the idea that we didn’t think that you know, a lot of them with severe cases were ever going to have an intimate life and that had really bad consequences. Because again, the bodies are the same and they change and if the individual doesn’t know why their body is changing, they’re going to freak out little bit and you’re going to see some behavioral issues, especially in non verbal individuals that you know, can’t communicate that they’re really freaking out over this. I like some of the explanations that Mike has for his son. And I think that the more specific, you’re obviously in the midst of the conversation with him Mike and you know, just start to get even more specific and go over all of the possibilities so that you don’t, don’t rely on rules so much because every rule really, you know, you’re almost appealing to something about them that can get rules. You know, that’s the temptation of this, that oh, he got that rule so I don’t have to teach him as much. But sometimes we rely on the rules a little too much and that can be misinterpreted. And a lot of the; actually if have a funny story about this that Peter Gerhardt told in front of his sexuality lessons. He was in a court case in New Jersey where this teenager with Asperger challenged him, severely challenged with Asperger stuff, and he kept going into this local mall and kept going up to women and saying, may I touch your vagina, may I touch your buttocks, may I touch your breasts, and security guards would, just you know, and the people would complain and security guards would boot him out, but he kept coming back. Low and behold, you know, eventually he’s arrested and Peter gets called for this case and they do a little digging and what they find, they find that this young man was only doing what he was being told to do in his sexuality curriculum. Which was, if you want to touch someone, you have to ask. So the lessons may need some modifications and I think that the more specific that you get with your son, now obviously when it comes to things like, when is right, especially when we’re actually talking about the sexual act, you know, when he’s ready for that, that’s when you really need to go into the parameters of getting deeper with the kid hopefully and if they need to take example from you, as their parent, they might need to based on their level of abilities. But it’s something that is an individual decision and I think you just need to come up with examples really basing each example on a specific type of relationship. Like on where he’s really, really in love with somebody; one where, you know, it’s a steady girlfriend and a nice sort of comforting thing to have from anywhere from one month to three years, while in school. Or just a casual girlfriend. You might want to go down all of those specifics. I mean obviously, this sounds like somebody that has some challenges based on the questions their asking and you just need to make sure that your son absolutely aware of what’s going to get him in trouble. But I kind of like the direction, you know, that you’re on with your son and so I would therefore say stay on that same pattern and grow with it and get more specific.

Chantal Here’s a question from Dee Dee in Bedford, VA. I heard that males are required to register with Selective Service within a month of turning eighteen regardless of disabilities. Is that correct? Does my son with high function autism have to register even though he cannot read at his age level and doesn’t have the same social skills as his peers?

Michael I don’t know.

Chantal I know the answer to this.

Michael Please, jump in.

Chantal I don’t know if they actually have to sign up within a month of turning eighteen. I do know that your son will receive a letter and at his home because my son, who is very impacted by autism received a letter. So, I thought, well not a big deal and starting reading down the letter and thought there must be a box somewhere here saying. Yeah, because it said reasons why you cannot serve your country and so I looked for a box that said, “has
“disability” and there was no such box. And any male that is alive in the United States and is not in a mental hospital or incarcerated, is eligible for military service. So, I thought it pretty funny because I was thinking, maybe they could take my son toilet train him for me. Because I know, that’s a going issue in my house. Even though he was over eighteen at the time, that was a joke, so it’s ok to laugh. But, what we actually ended up doing on the letter was, I made my own box and explained a little bit about Jeremy’s situation and I sent the form in and I’ve not heard from them since. So, I hope that’s helpful. I don’t know what happens when you have someone who has high functioning autism. But, that is a very good question. But I do know that they are very serious about their forms so I would, if you receive a letter, I would fill out and I would do the same kind of thing. Make my own box and explain the situation. And if you have a medical professional who, if you have a letter that’s explaining the diagnosis or how it impacts his functioning, you might want to have that ready in case anybody wants to ask you more questions. What do you think about that Michael?

Michael Well, Dee Dee also mentions that her son has high functioning autism. And that’s the way she put it and she says that he can’t read at his age level. But she doesn’t say he’s light years behind his age level. And she says he doesn’t have the same social skills as his peers. That doesn’t say that he’s light years behind. In that context, he may very well be eligible.

Chantal I have no idea how they ascertain that. And that’s why

Michael Well Chantal, we don’t, we can’t ascertain it either. You know, that’s part of the thing that we’re learning about the diagnosis. I’ll be honest with you, I don’t want my son, you know, going into the service. That would scare the hack out of me, but at the same time, on a civil rights level, now this is not, you know, a concern that mom should be, you know, concerned with that’s just to throw it in there. As life becomes better for all of your children and as the world becomes less and less by their behavioral differences and therefore after that the anxiety, anger and depression, that I talked to you about starts to lessen, and we start to see very, very different people. Still with the same diagnoses, but just behaving very differently because of that loss of that anxiety, anger and depression, they’re going to be capable of anything whether it appeals, you know, appeals to our, you know, personal sensibilities of what we want for our children’s work lives. I’ll be honest with you, I was asked to get involved in a case years ago, just shortly after we invaded Iraq, and it was a pretty challenged autistic kid who really just plays war video games 24/7 and they, a less than honorable recruiter, sort of had private conversations with this kid and signed him up and this kid was clearly not ready or not able for something like that. And for many people who opposed the war, as well as opposed, you know, this kid that had been absolutely shanghaied by this really immoral recruiter, they want to get us involved in the context of, you know, you can’t let them sign up a kid like this, you’ve got to get involved in this and I wouldn’t touch it with a ten foot pole. Just because of the whole possibility that if a kid wants to go into the military and can do it, and I know a lot of people on the autism spectrum that can do it and then do, do it, you know, the military is, you know, we think of places like the arts and university life as being the best place for a kid on the spectrum, because they’re the most behaviorally permissive. You know, if that person yelled at you, he’s a genius, you know, he can yell at you or something like, idiotic, like that. But the military can be just as attractive of a life, based on the fact that they tell you what to do from the moment you wake up until the moment lights go out at night and that, you know, not having to interpret anything. That’s a life that’s heaven for a lot of people on the spectrum. So, that’s probably long outside, you know, your question Dee Dee and I hope you’ll have forgiven my having gone outside that, but I’m just glad that Chantal was there to answer it. But it actually does touch on some really, really bigger issues which we’re dealing with and I thank you for being patient with me.

Chantal I think it really is like many things on the autism spectrum, it’s very individual. What’s appropriate
Michael Absolutely. And that’s what confuses everybody, but unfortunately, it’s just the truth. This is a very complex gradient and every attempt to draw a line in the sand where Asperger becomes autism and vice versa, has been proven wrong in practice. And everybody improves, you know, so long as they get the right services. It’s just one really complicated, complicated, I wouldn’t even say gradient, because that’s one dimensional, you know, there’s three dimensions. There are shadings along the way and I guess it goes back to that great phrase, “that if you met one person with autism, you’ve met one person with autism”.

Chantal Right. So now, I’m going to refer to some of the questions that have come in about vocational and college. Some of them are a little specific, so I don’t know if you’re able to answer them, but you might be able to tell people where to get resources. Here’s a couple from Jennifer Esum from Pennsylvania. Especially in the state of Pennsylvania, are there any kind of training or vocational programs that may be helpful, to help them live as independently as possible?

Michael I don’t know exactly which ones they are, but I do know that in Pennsylvania there is actually a lot going on. And what I would have Jennifer do is contact our regional facilitator in Philadelphia, which is Bob Fadeen and maybe ask him for some resources. There are also a lot of great groups. Actually, the really best group for her to contact would be Ascend in Philadelphia. Which is a parent’s organization there.

Chantal How’s that spelled and how can she find them?

Michael I think it’s spelled the way the word is. I know there’s another Ascend in California which I think plays with the spelling of it. But I do think its A.S.C.E.N.D. It’s like the Ascend Network of Greater Philadelphia. If you get a woman named Deidra Wright there (W.R.I.G.H.T), she’s absolutely wonderful.

Chantal Right. And here’s another question from Jennifer. What are the colleges that I’ve heard about for special needs teens, young adults, post school? Also, where are they? And would they be something to consider for an autistic individual?

Michael What is the first part of the question again? It just didn’t grammatically make sense.

Chantal What are the colleges that are available for special needs teens and young adults?

Michael Oh, ok. I didn’t hear that word “available”. Ok. Well depending on that particular kids abilities there’s a lot of options. There are colleges that do what’s called residential assistance programs. And those are not cheap. There’s no federal funding for them unfortunately. But if you look at something like what Michael Mammon has set up with the college internship program, he use to be a board member of ours, and he’s got campuses in Brevard, FL, in Berkeley, MA, somewhere in Bloomington, IN and he’s got two new campuses, one in California and one elsewhere and a lot of copycat programs have sprung up where you have these living facilities outside the college and also outside the college tuition I might add, where there’s staff there that teach the kids independent living skills while they’re going to college and you know, having roommates and dealing with all that sort of stuff. Learning how to cook, learning how to clean, as well as providing academic assistance, tutoring, if there’s need be. But you also have to remember that every college has to have an office of student disabilities, unless they’re a religious school. Now, you should always do your homework, that having been said, on whether or not, you know, it’s federal law that the colleges have to have that office of student disabilities. And you want to do your homework on which ones are really active in helping their kids with disabilities to navigate life on campus and which ones just put the
janitor in there on Tuesday’s to pay lip service to federal law. That they are really resentful they have to do anything. You need to do your homework on that. The other thing to take a look at is the real protections that you have and in this particular case, it’s Section 504 of the Rehabilitation Act and it’s also the American with Disabilities Act. And what you will need to do, this is very similar to what happens in the workforce, is if there are problems or there are challenges, in the class, now this doesn’t have anything to do with the social life, but if there are problems in the classroom, then you can request, usually with the help of a therapist, and this is something you should submit in writing, you can request certain accommodations within that classroom structure. This is not the same however as I.D.E.A., which you all, I’m sure are familiar with, and which basically says that your child is entitled to a wonderful education and one in which they will help you figure out what your child needs in order to succeed in the classroom. The difference between I.D.E.A. though and Section 504 in ADA, is that it stills gives the school the right to kick your kid out and you have to be the one to come up with the strategies for what’s going help your child succeed. They don’t have to help you along with that. So you’ve got to be the one, usually with a therapist, to come up with, you know, again, those ideas and there’s a great list actually in my book of some of the ideas that you can request once, you know, you’re realizing that my kid is having some problems in this particular classroom. You could ask for a person to act as a note taker, just sort of going by memory here, you can ask for permission to use a tape recorder, additionally time when they’re taking test, written instructions to back up any material presented orally or by the professor in class. You can ask for review sessions and socially through the Office of Disabilities, you could ask for parent support groups. Sort of like what we do at Grasp, where that office will help to organize all the kids who also have autism and Aspergers syndrome and you know, just provide something like a games night where they can get together once a week or once a month.

Chantal I just want to say though, Michael that we have to be careful when we’re advising parents because there’s one thing that’s a big difference between your student before the age of eighteen and your student after the age of eighteen or when they’re in college. Because when they’re in college, it is up to the student to advocate for themselves and to be able to ask for those strategies. You might be able to advise your child, but the college will be talking to your student and they won’t be talking to you if you at a regular college campus even with a disabilities office.

Michael That is absolutely true, Chantal and I appreciate you having thrown that in there. And it’s one that I just made a boo boo on. For whatever reason I sort of was assuming that this is pre-college. And that if you know what these challenges might be in advance, then mom or the therapist probably would be helping. But you’re absolutely right, when you’re in the environment, this is my bad, your kid has to be the one who advocate for themselves. Maybe a phone call to mommy or a phone call to the therapist, or consulting with the Office of Student Disabilities. A good Office of Student Disabilities will help your child come up with what specific ideas to request. But you’re absolutely right. They have to be the ones to make those requests.

Chantal Which is why it’s so important to teach them advocacy skills while they’re still in high school.

Michael That’s right. And you can’t teach advocacy skills unless your kid knows exactly what they’ve got.

Chantal Exactly. I realize that we have a lot more questions that people have been sending to me, so I’m going to try and move a little faster here.

Michael That’s alright. I’ll try and be a little bit, that’s you’re signal that I need to be a little short winded too.

Chantal We both do. Ok, let me try and find the one that has to do with work and college, then we’ll go
back to some others. This is from Nancy in Watertown. How can I motivate my twenty-three year old son to find a job? He has Asperger Syndrome.

Michael Well, right off the bat, that’s hard for me to answer not knowing your son. I mean, there’s the question, does he want a job? Does he want a job and just doesn’t really, you know, have that work ethic yet that’s going to be required to get one. Does he have the social skills to be able to get through the interview process? And if he doesn’t want a job and if he, you know, wants to stay at home forever, and ever, and ever. This may have to do with a little bit of depression. And it just may require thinking about, you know, ways in which to trick him into wanting whatever his version of the American dream is going to be some day, rather than anything else. So, I guess the only question I have is to look at why it’s not happening.

Chantal That’s a good point, Michael. Here’s a question from Stacey in Winter Haven, FL. I have a son with Asperger who is almost nine. He has found the private parts. I’m thinking that this is kind of early. What do you suggest and what do the teenage years have in store for us?

Michael Stacey, it is kind of early, but it is not drastically early or ridiculously early by any means. You know, kids have erections at that age and you know, just touching them quite easily reads as something that feels good. So, it’s part of the sexuality problem we have with really, really severely impaired folks is you know, convincing them that just because something feels really incredibly great, you can’t do it anyplace you want. So, I don’t know if this whole anything, you know, aside from, you know, where and when, you know, it’s appropriate to touch himself and where’s it’s not, more importantly. So, I don’t know if those teenage years hold anything that drastically out of the norm for you.

Chantal I think that’s something that really been helpful for a lot of people again on different parts of the spectrum, is to teach the child the concept of private and public and if you need a visual aid with that, you can have like a icon with a stick figure who has all his clothes on that says public and an icon with just underwear that says private. And you teach them what’s appropriate privately and what’s appropriate in public. So when it gets to touching body parts and the eventually masturbation and then also when you try and teach them the difference between private conversations and public conversations. For example, something that’s appropriate to talk about with the family at the breakfast table, which may not be the same conversation that’s not appropriate to have in the lunchroom cafeteria. Once they’ve understood public and private, it makes it so much easier, wouldn’t you agree, Michael?

Michael Agreed 100%

Chantal Trying to think of practical things that might help somebody. But you’re absolutely right Michael, but I had to bring up the private and public because as Michael has pointed out earlier question, it’s so important that they learn what’s appropriate in public and what is not. Because they can get into so much trouble.

Michael Yeah

Chantal Legally and so forth. Ok, Denise in Kansas. My twenty-one year old son has autism with some Asperger characteristics. He has problem talking about and facing his diagnosis, although his is aware that he has autism. Is there away to help him understand and face this aspect of his life?

Michael Well, the first trick is, I mean obviously, he’s been told what he has, but maybe look back and this is not, forgive me, this is not to say blame the parents, but you know really check to see if you have any work, you know, any back up work to do. But when an individual gets told there’s a big difference between what’s going to happen to that kid, if they get told that
this good news or if this is bad news. And it is good news. Because now they’re going to have answers for why they might seem different from everybody else. And that’s going to help them enormously. You take the kid that has the sensory integration reaction to the school bell going off in the hallway and, or you take two kids that have that same sensory integration reaction, both on the spectrum, but one knows what they’ve got and the other one doesn’t. The one that knows what they’ve got and the bell goes off and they’ve got that reaction and it stinks. The second one who doesn’t know what they’ve got, walks down the hall, the bell sounds and it stinks, but there’s a second layer of why am I going through this and nobody else is? I feel lousy. And if maybe the child has had, you know, and I’m not assuming that he has, forgive me if this is really, really not true, but I just have to cover all bases here, but if the child has had a lot of negative iconography having to do with the diagnosis in his life, whether its words or images, you know, I mean there’s plenty of publicity campaigns out there, you know, telling you what an awful thing this is to have and you know, well our population can read and those words hurt a lot of the times. He also might just have a really strong work ethic though, where he is just one of these kids that doesn’t want to have any excuses and barrel on and do just the same things that every else does. And in those cases though, it’s usually best to just say that these are not excuses, these are explanations and to sort of try and get them to see more positive examples of people that have the diagnosis. There’s a great book by a woman named Jennifer Elder, called Different Like Me. And it just list a lot of these really famous people that have been diagnosed in retrospect of having autism spectrum conditions. There’s an entire page full of names that I use in a lot of presentations that’s just from three books. People like Albert Einstein, Thomas Edison, Thomas Jefferson, Beethoven, Mozart, Glenn Gould. Granted, diagnosing the dead is, you know, has to be a pretty arbitrary process and I would never do it because I’m not a clinician, but I like have those positive examples to show people. Because in the past, the only positive examples we had was to what was possible if you had one of these diagnoses was working in, you know, as a cashier at the flower shop in the hospital. And if you really, really provide a lot positive role models for them either directly or indirectly, it can somehow relieve a lot of the negative iconography that comes with these words and that we’re still battling.

Chantal  Ok, while we’re on the topic of positive images, I wanted you to mention briefly about that list in your book that I think is really wonderful and a perfect example of how something can be found either negative or can be found something positive. And that’s you describe the characteristics of someone on the spectrum. Did you want to mention a couple of those, Michael?

Michael Well, if you look at, you know, when we see a characteristic of the diagnosis in those bullet points that we see in books like the DSM, or in any of the internet sites that list what are the characteristics of this diagnosis. There’s an interpretation that explains what the characteristic is and we sometimes get a very cold and kind of stigmatizing, you know, description, so sometimes we get very negative viewpoint of this particular characteristic. If you look at, let’s say, the characteristic that the kids have a really intense absorption in a field or topic of interest, you know, description, so sometimes we get very negative viewpoint of this particular characteristic. If you look at, let’s say, the characteristic that the kids have a really intense absorption in a field or topic of interest, then you get something like, the individual’s obsessed and is driven further into this absorption by anxiety and stress. Now, I’m somebody who actually hates the word obsession, because usually what we’re talking about is something that in their eyes is a passion and a passion is a much more positive word than an obsession. And usually kids on the autism spectrum have an ability to bury themselves in work, to the exclusion of everything else, work that they love to a degree that sometimes is their best chance at getting that career and you don’t want to kill that ability to have that kind of passion. But the more positive interpretation of again this intense absorption in a topic or field of interest, could just be, the individual is passionate. That sounds a lot different than a critical interpretation. You could go with the professorial, monotone manner of speaking. And what’s right next to the bullet point would be something like stilted awkwardness that is off putting to others; often preventing further steps in a
potential relationship. But you could also spin it as, focused on being clear on what is
being said by utilizing the strength text. A discomfort or inability to small talk; the
individual sees no logic in it. That could be read as off putting and impolite or it could be
read as “hey, this guy gets to the point” and for a lot of people this could be really
refreshing.

Chantal So….

Michael Yeah, go ahead

Chantal What I was going to say is that those are very good examples. I’m hoping that helping people
who are listening. Should I ask another question?

Michael Absolutely

Chantal Ok, this is from Deidra from Deverna Park. She asking a question, we seem to have more trouble
with meltdowns that before. My son just turned fifteen, but given any discipline or
correction, causes them; causes the meltdown. This makes guidance very difficult. Any
suggestions on how to discipline at this age, without causing major disturbances?

Michael Well, a lot of times with meltdowns you’re dealing with somebody that may not be overwhelmed,
but certainly feels it. You have to be careful with discipline because it’s how, it’s not, you
know discipline is actually quite good. But it’s how its implemented that’s is going to be
very, very key. When we’re very, very young, we sometimes get it that things are not
working out for us with our peers, as they are with other kids. So, what do we do? We
grab on to mom and dad a little tighter and their words of praise and criticism starts to
mean maybe a lot more than in a normal relationship, they should. But that’s not going to
change, so you’ve got to adapt with it. My son thrives on having rules that have
consequences and lots of them. I did not grow up in an environment that had a lot of
rules, so I was a little surprised to see him become this kid that really thrived. And in an
environment in which there were rules and consequences that were immediately
implemented if a rule was broken. No negotiation. Well a little negotiation. But the trick
is, I don’t impose any kind of, “you’ve disappointed me” message into it. I don’t
incorporate any after effects. The consequence is implemented and I’m back to loving
him and caring about him. But you know, being friendly with him, just as I was before
this particular incident happened. And I think the trick is that, you know, any kind of
instruction has to, you know, consequences, has to be doled out as instruction and not
criticism. Because that criticism just might be what ‘s sending your kid of the edge.

Chantal Very.

Michael It’s that Mr. Spock portion of things that appeals to their mindset, which might even have an
advantage because the kid is on the spectrum. Because, you know, they just don’t
experience emotions, may be like, most folks. And, I certainly didn’t. And if somebody
just, you know, when I was a kid, would just say “you have to do this and this” because
it’s just necessary. I’ll go as far as to say I’ve come the point in my life where I
actually don’t even believe in punishment, as an idea that works. I do believe in
consequences and I believe in implementing those consequences very quickly and
without negotiation. But I don’t subscribe to putting any kind of personal reaction along
the consequence. I think that’s where the problem is a lot. Like if he sees mom or dad
get upset, a lot of times in the past we thought that was a good thing, because mom or dad
were exposing more of themselves to him. Communicating to him where they were at. I
actually don’t think that’s a good idea. I think it’s better if he sees that mom and dad are
still there, what he has done has not destroyed their world and that it’s just something that
he’s got to learn a cognitive level.
Chantal  Ok, now Angela from Kansas.  With these types of kids, why don’t they have specific careers that fit their familiar routine type of personality?

Michael  Well, I’ll preface this answer by saying that I don’t think any kid, you know, I think any restriction should be imposed on what careers are possible for people. I think that the diagnosis presents challenges which will require them to work harder than others to obtain certain careers. I think, you know, it may even present attributes which make certain careers easier than others. But, there’s been a lot of stereotypical, you know sort of pushing kids into fields like IT work, you know if they’re good with computers, or you know, clerical work, if they’re good organizers, like kids on the spectrum are, but a lot of them are really good at organizing. And professions like you know, if you could get your masters in library science, then you’ve got a really decent paycheck. So you know, to be able to build a home out of. These are sort of the stereotype ones and sometimes it can vary from kid to kid, you know, math abilities are very often prevalent in kids on the spectrum. And you know with that comes music a lot times because what is music when you bear down to it, but counting. Careers which have stereotypically not been the best idea are things, you know, anything having to do with interpreting non verbal social queues, likes gestures, tones of voice, and so you know, customer support areas, sales jobs, you know, these have been professions that have had that red flag of stay away from. But I think these can be obtainable even if it’s good to know at the offset what the kid is going to be predestined to be a little bit more challenged at and what the kid is predestined to be a little bit good at. And that really varies on the kid.

Chantal  Ok, here’s another question named Angela. Do you know of any teenage conferences or Facebook type sites where these kids can meet, communicate with each other between the ages of sixteen and twenty-one?

Michael  I don’t actually. We have a teen Yahoo group which you can subscribe to off our website. But I be honest with you it had very little activity and I would love to see it get off the ground. So, she could maybe help us out and help get those conversations started. Because we have kids that have subscribed, we just don’t see any activity on it whatsoever. There’s one that Delphi Forums used to have. It’s delphiforums.net. The Delphi Forums throws a lot of its advertising on you and in order in their free zone, you have to put up with a lot of the pushy advertising for them, you know, trying to sell you on how much better group A is and that can be really annoying after awhile. I would just try getting the Grasp Teen Yahoo group going a little bit more.

Chantal  Ok, that sounds interesting. We do need more of those kind of things up there.

Michael  Yes we do.

Chantal  Ok, here’s another one. Here’s an interesting one Michael and its personal so maybe perhaps you may not want to respond, but it’s from Barb in Nashville.

Michael  Oh please, Barb, shoot at anything. I mean, I’m to a fault, open to anything

Chantal  Ok, how did your diagnosis of AS affect your marriage?

Michael  Well, I think that it was really good in the context for all the times that my wife had thought that I was rude to her, she found out I wasn’t, that I didn’t intend to. You know it’s the old, how do I look, you know, do I look fat in this dress? Yes, you know conundrum. And that made things a lot easier on her. I think that there was, I’ll be honest with you, I’m on my second marriage now. And I was, at the time I was diagnosed, I was still on my first marriage. I don’t think because she was the one though that had actually been the first to sort of trick me into reading an article on Asperger Syndrome regarding our son when she had in her mind that was something that really included the both of us. She was actually
very, very supportive of getting the diagnosis, finding out a lot about this other stuff. She and I were just, it was a very amiable break up and we’re just, you know, good friends who admired each other’s work and who when we both got married for reasons of our own, we just didn’t understand what real love was and once we came to realize that, it was kind of a really, mutual, not so tragic and not of disastrous experience for us. But I will tell you that I have seen a lot of other times that the partner that doesn’t have AS in the marriage, very often, can sometimes try to blame all the problems of the marriage on the AS and in my experience, there’s never a good guy and bad guy in a marriage. My first wife had some issues of her own. People come together for very good reasons. Whether those reasons have a name attached to it or not, they usually at least find and they know enough about each other, or they should, that it’s a good fit. It depends on whether it’s going to be a good fit forever is going to depend on a lot of hard work and a lot of hard compromise. And you know, also whether or not it’s the real thing. I’m trying to sort of think and remember back to that particular time. I think most of all it was, I mean, you know even though the marriage ended, I know this is going to sound like a weak argument, but I really actually think it helped because it really clarified not only for me, so much of my life and made me feel better about who I was, but if your partner who they are, your life is going to be easier.

Chantal Right. Even for people not on the spectrum

Michael Absolutely

Chantal So, quite a few more questions here. Here’s one from Janice Lawrence from Kent. I have an eleven year old who spent most of his school years in self contained classrooms, with very little integration, despite numerous requests for inclusive with his typical peers. His behavior has always been in the way. Can you advise how I can convince them to provide more inclusion opportunities for him? He is academically bright, but is verbally and socially delayed. I am fearful of the junior high years which are to start next year and afraid he will be stuck in a self contained classroom when he graduates. Social groups are few and far between here and we don’t have family nearby to practice with. I really want him to be retained for another years work on his social skills, but don’t really think that’s going to happen. He’s having his three year evaluation soon and the retention issue is yet to be decided. Any advice would be appreciated.

Michael Well, number one you have to look at that question of desire. Does this kid want to interact with those other kids? Another words, does he put in an effort to change certain social patterns of his. But the other thing is that it sounds to me that you have that right to change the IP, especially if you have this three year evaluation coming up. So, it should be something that’s fairly easy, not fairly easy. Nothing in the school boards is fairly easy, but compared to some of the other nightmare scenarios, this one sounds like it would be a lot easier to be able implement just by changing the IP. In terms of changing his, if he’s really, really happy in his self contained class right now, if he’s really, you know, sort of at the top of the class socially and just needs to kind of branch out, I can understand that. But if he’s sort of more in the middle and he’s just really happy where he is, I’m not so sure I would push him. Or at least have an escape hatch that he could go back to if it didn’t work out.

Chantal I think also that, she, or this parent seems to be asking for at least more inclusion opportunities, even if he’s not always, not total, integration, but I, it is true what Michael was saying that you have the right, but it’s really up to the school district to prove why your child should not be in general education. You can always have your child’s mainstream changed for a few classes a day, if that’s what would be good for him.

Michael Or even just one class a day.
Chantal Yeah, they may try to tell you that academically he can’t fit into this class or that he’s not at this level, it doesn’t matter, you can base it on social skills. Because everyone needs to know how to sit with other people and how to be around with other people and that’s really just a basic thing, but Michael’s right in saying that you have to be careful in seeing what is your son’s comfort level. But it’s true that even if his comfort level is that he doesn’t want to be at all outside that classroom, I think he needs to start little, by little having that opportunity because his whole life is not going to be self contained.

Michael Let’s just take a nightmare situation where, you know, that’s say the school board wants to put a fight, you don’t have the money for a special education lawyer and the school board is going to win ugly, ugly muscle. You can get him involved in some after school things to see how that works. Whether that’s sports, or scouting, you could use those as your experiment.

Chantal That’s a good idea too. Ok, here’s one, Marvee in Houston. I have a twenty-two year old son with autism. He does not want to wear clothes. Currently receiving ADA. I’m unable to take him out because he will not keep his clothes on. I have tried some therapy, but he would not go into the therapist room. Any suggestions?

Michael That is difficult. I’m glad he’s getting the ADA. I think that the sensory specialist is going to be kind of key here. Because the clothing might very well be a sensory issue as opposed to a willful rebellion sort of issue.

Chantal Maybe the therapist can go into the home or at least give mom some advice of what to try.

Michael Yeah, I mean you can also just trick him. Maybe, you know, if this child is aware that, you know, that’s so many unknowns in this particular case. You know whether or not the kid has a general distrust of clinicians, whether the kid is sick and tired of going to the doctor’s office. All these issues seem to come into play in terms of finding a really, really good solution. I mean if this kid

Chantal This is a man. He’s twenty-two. This is a young man.

Michael I say a kid developed mentally, obviously. I wish I knew more, I wish I knew more about what type of reaction he has.

Chantal That’s a hard question. Maybe I should ask for some more information?

Michael Yeah, write some more information if you can, ma’am, and get it to us. It might help us. But when I say trick them, you know, if that sensory therapist can come to your home, you know, maybe just announce the person as a babysitter for a little bit, and see what happens.

Chantal That’s a good thought. Here’s a question from April Lamorrow. Why is it ok for some teachers to limit the powers of children with autism? I believe my daughter can do anything. And I would never say that she’s only good at wrapping silverware. What are your thoughts? I guess they are having her busy wrapping silverware with paper towels or napkins.

Michael Well, some teachers are incredibly stupid. It’s a profession that should probably be one of the highest paid of any profession on the planet, and is unfortunately one of the lowest paid, but one of the fine things about making it one of the highest paid, is you get rid of some of the dumber ones. Information again really, really trickles down and it may just be that we all have good and bad teachers. Hopefully, the next one won’t be as bad. I think you just really need to go over this particular teacher’s head and talk about what a negative influence limiting opinions of what her daughter can do are doing to her. And talk about how much more positive approach that preaches the possible as opposed to the probable.
Even if the probable in this case is right or wrong, you want to have somebody that believes that your child can advance. I would just suggest that you go over this teacher’s head and lobby very, very strongly for this and even if they can’t fire the teacher or get you a new teacher or something like that. Hopefully, some system of accountability will be placed on this teacher where they now know that it’s not just the mom that knows how negative that they’re being with the child.

Chantal  Good suggestion. Here’s a question that I really like, Michael and I’m hoping you can help this woman. Susan from Birmingham. How could you deal with the stubbornness issues, especially when the child insists that he is right and you, the mom, are wrong?

Michael  Knowing about the diagnosis. Understanding the dogmatic, black and white way we sometimes think and then cognitively getting him to understand this is a process and not going to happen overnight. But getting the child to understand that the strength of his argument and the soundness, logically of his thinking is not the most important factor in this person to person relationship. So that it’s not, you know, if you confuse that kid’s cognitive pragmatic mindset and twist it around on him, and include a pragmatic message that they are often wrong, and we are. We get ideas in our heads that are so sound logically, that we can’t believe that the rest of the world doesn’t operate like this. Chantal very nicely rattled off some of my career achievements. Let’s talk about when I first got out of graduate school and I had a master’s degree in playwriting and which for economic reasons you mind as well put that degree under the bottom of a birdcage. So I had to go out and find other jobs and go through the whole temp thing trying to find stuff and every time I would go into a new job, I would immediately impress people because of my work ethic and because of what I could do right off the back. And I would start to get impressions about how that entire business worked and they were so solid in my mind. They were so absolutely, you know, it just worked. And not only was I wrong about how that business worked always, but I had to understand the cognitive notion that my opinion on how that place should be run was not as important as the boss’ opinion and the boss’ opinion mattered more because if I wasn’t doing what the boss wanted me to do as opposed to what I thought I should be doing, I was going to lose my job. And that’s just the way the world works. Now you just can’t say, that’s the way the world works until you’re blue in the face with a clue of AS. You really have to start to get them to cognitively understand the diagnosis because once you do that it won’t be so negative when you hit them over the head with you’re wrong an awful lot, you may think you’re right, but you’re wrong an awful lot. And now if I prove that you’re wrong, will you take this to heart the next time you know, you get really, really zealous about another idea in your head? It’s a long process of whittling that particular hard-line edge down to something softer.

Chantal  Ok, now Barbie for Houston has written a little more information here. She says, that’s the one with not wanting to keep his clothes on at all. She can’t get him into the sensory therapist’s office.

Michael Oh, thank you Barbie.

Chantal  My son is non verbal. We can keep shorts on him, but only if we keep him busy, but only for short times. He will not where shirts, underwear or shoes. He started by not wanting to wear underwear or socks, then progressed to not wanting shirts. Now he doesn’t want to wear anything. That sounds like a lot of sensory integration.

Michael No, it doesn’t

Chantal  No, you don’t think if does? I think it does.

Michael But if he could take clothing earlier. It’s gotten worse, not better.
Chantal But just because when she said he started by not wanting to wear underwear and socks. Those are tighter things, so he was ok with looser clothes.

Michael But he used to be ok with shirts and now he’s not.

Chantal That’s true. It sounds like it started with one little thing and then it got worse

Michael Yeah

Chantal It’s really hard. I’m surprised the ADA people aren’t able to address it. But I still would want to know about the sensory integration person has to say.

Michael I would too. It’s a nothing, if not worth a check. You know every behavior has an origin. And the problem is the more you get into really challenged areas of autism is finding out what the origin is. Where that sense of distrust, discomfort or confusion, lies and be able to communicate something that makes that individual feel a little better. And this is all about communication, this is all about whether it’s a high end of Asperger, a low end of autism. I mean its two worlds trying to communicate with each other and often failing, because we just don’t know enough. And I would also, well if the kid is getting ADA, that should be covered in that. I’m trying to think of another therapeutic approach to this other than the sensory therapist and the ADA practitioners, but I’m just not coming up with anything.

Chantal I still think it’s necessary to find out more for the sensory integration person

Michael Oh yeah, I agree. I just don’t think in the end, you got to because it’s a possibility. But I don’t think it’s a probability. If the kid was comfortable with things before, usually, you know, you do see improvements. Even if it’s not at the speed you want. But you don’t see regression in sensory integration issues, usually.

Chantal Sometimes you get into bad habits. So for example, he started having less and less clothes on. And he was permitted to do that, and it kind of goes downhill from there. I’m just saying this as a parent, I know like with my son, if we give me a little slack, with a behavior and get a little loose on the rules, and all of a sudden, six months later we’re like how did we get to this point. But I think that the ADA people should be able to help with the desensitization program and I’m sure his mother has tried a lot of different things but where he wears his clothes for a certain amount of time and then adding to that.

Michael I was going to add to that idea, but saying just garden variety, positive reinforcement. Where if there’s an activity that the kid loves or a food that the kid loves, you’ll get more of this if you would wear some clothes, and see what happens. Or if, this is very risky, but maybe, subtracting certain pleasurable things, you know, if the clothing doesn’t get worn.

Chantal The good thing is that if he is having AVA, then you have a professional there to help you with those kind of things

Michael Maybe, you might want to switch ABA therapist. Again you might be dealing with somebody, again we may be talking about the singer and not the song. You know, having somebody teaching the appropriate therapy for your child, but just isn’t very good at it.

Chantal Maybe they’re use to a different type of person with autism. You know, older or younger. We have only nine minutes left, no actually eight minutes left, so let’s move on here. Here’s an interesting question, Tony Cochran, in Snellville. How do you get an adult diagnosed when they do not realize that they are? Very hard for our grandson, who has been diagnosed with PDD to relate to his father. The father has a PhD and continues to blame the mother and disputes the diagnosis. I think the question is actually, How do you get
an adult diagnosed when they do not realize that they are? Well, first off, that would have to be a professional doing that. And ah, very hard for our grandson, who has been diagnosed with PDD to relate to his father. The father has a PhD and continues to blame the mother and disputes the diagnosis. Any suggestions for that part of it Michael?

Michael Well, I do and I don’t. I have an observation, but it’s not a pretty one. The one thing I’ve always found that I can’t do anything about is denial. You can plant the seed and sometimes the best result is simply to provide consequences. Now more marriages have ended because of one partner’s inability or unwillingness to look at themselves in the mirror for this diagnosis and they have by getting the diagnosis and that’s probably by a 100 to 1 margin. This is an individual that we have to remember probably grew up, you know, these words had even darker connotation to them when they were heard, then they do today and more negative stigma. And then if something like this applied to you, then you really were a broken individual and doomed to second class citizenship, and a lot of other bad things. There’s an amazing Twilight Zone episode from sixty years ago, when this really racist guy wakes up one morning to find out he’s black and I see this a lot with folks the grew up that may have been bullies at one point to kids with special needs and one day they get the diagnosis themselves. I’m not saying that this person is definitely that type, but if you’ve grown up with certain ideas about disabilities, if those were some more of the negatives ideas, then this process becomes even harder for you. The question definitely needs to be approached in a really gentle, again to say this is good news and not bad news for you or if at the least the person can either read my book or Tony Attwood’s first book. If they want a more clinical prospective, not Tony Attwood’s later book, but his first book called Asperger Syndrome from 1988. Don’t get the complete guide to Asperger Syndrome, from two years. I just don’t think it’s helpful in this situation. This individual might lose people that he loves and that would be very, very sad, but maybe threat of such a loss is the only thing to make people realize, I need to look at this for myself, because I’m just making everyone else unhappy by my unwillingness.

Chantal Right…..uneasy situation

Michael No, it’s an awful situation

Chantal We only have four minutes and I’m going to ask you a last question, ok?

Michael Ok

Chantal My son is very unmotivated. What are some ways to get him motivated into doing things? The person did not put their name, so that’s why I didn’t mention who it is.

Michael Well, I think we were asked this question a little bit like the kid that wouldn’t go out and get a job.

Chantal Right, but this one is sort of the same issue, because it all has to do with motivation, so.

Michael Right

Chantal Just wanted to know, because people do bring up the motivation aspect. Do you have any little hints of advice for us about how to get some on the spectrum motivated? Doesn’t matter if it’s for a job or for school, but it is a big issue for many people.

Michael Well, I think really, sort of outlining what the long term plan is going to be them if they continue to go unmotivated, and what the long term plan will be for them if they can get motivated. And if you can kind of sell them, rather than tell them, one why it’s in their best interest to go out and do things, that’s maybe going be a huge part of the equation. But if the person is just really depressed and has had a truckload of bad experiences,
where they just don’t have any energy, then that’s when you need some garden variety therapy for depression with a therapist that knows their AS a little bit. Then again, they may need the same positive role models in those books and all those famous people, if their feeling depressed in particular about maybe having really negative feelings about the fact that they do have the diagnosis. Trying to change that into a positive feeling.

Chantal  Giving them role models. There are books out there with role models about people on the spectrum.

Michael  Yeah, the books that name of these famous individuals diagnosed in retrospect.

Chantal  That’s correct. Well Michael, its been a pleasure having you here on the seminar. We didn’t answer absolutely all the questions, but practically. I want to remind everyone that they’ve been listening to Michael John Carley, who is the Executive Director of GRASP and also the author of Asperger's from the Inside Out - The Supportive and Practical Guide for Anyone with Asperger's Syndrome. And you can find out about GRASP and about Michael on www.grasp.org. Thank you so much for being here this evening, Michael.

Michael  Chantal, my pleasure. And if I could just add one thing on the book and that is that, the book is for those individuals being diagnosed late in life, but half the market, as we sort of knew that it would, was for family members and clinicians, that sort of get an inside track as to what their loved ones might be going through.

Chantal  Very good point that it’s very useful for parents of kids with autism. I found it extremely useful. Just understand, because you explain your life story growing up as a child and it can help you understand what it’s like for someone, for your child, facing this everyday at school. Thanks again Michael

Michael  Chantal, thank you and thank everybody for calling in or listening.

Chantal  Goodbye everybody