

EUSTACIA CUTLER
CONVERSATION WITH DADS
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A conversation between
Eustacia Cutler, Thomas Mead, Rich Weinfeld, and Robert Naseef

Eustacia. And here is our other third, Rich Weinfeld. So, we are now three of us, Robert Naseef, Tom Mead, and Rich Weinfeld and I'm here, Eustacia and I thought to get us started I would give us a little agenda here to work with. I was going to start off with Robert Naseef because you are the accredited psychologist and you have already established a dad's group. I thought in light of the little story I sent which I was just saying to Tom, was an incident that happened out of Dixon, IL where I met Tom Mead. The boy, the young, he was a boy to me, believe me, he was a boy, the young father who was angry and upset. Then, covered it up in the end, backed away when I tried to reach out to him to wish him well at the end, he didn't, he closed off. And why I'm starting with you Robert, is we talked earlier about that moment of how you get a dad to commit to come to a gathering of other fathers. How do you get somebody, like this young man...

GETTING DADS TO PARTICIPATE

Rob: Well, I mean in my experience and I was just in Baltimore Saturday for their Autism Society yearly and about 40 dads came to a workshop I did but most of them came because their wives or girlfriends or significant others told them to. Now, they got a lot out of it once they were there. But I think a lot of people that are going to read what we put up or see what we are doing are going to be women and they are going to talk to their partners about it.

Eustacia: You think they are the ones that are going to help bring them in

Rob: Yes, I mean I just talked to a guy in Seattle, WA who is very active in the Father's Network out there but he said the way he got involved was his wife threatened him.

Eustacia: Ah...

Rob: And that's really a common thing.. You got to do this .. It's too hard to live with you. That kind of thing.

Eustacia: Well, now that brings up the other question I had for both you and Tom. I don't remember if I attached it onto the end of the other story, but the two mothers that came up to me and they were very small women, and they were worried about their sons who are now in puberty who were bigger than they were and were violent. And I said, "Well, what about your husbands?" Well, one was a trucker and one was a farmer and they said "Oh they are too busy." In other words, they had backed out of the situation. Now obviously, the mothers had tried to suggest that they needed help and I said, "What will happen if they come home one night and find you beaten up?" and that's exactly what these two women feared.

Rob: Sure, sure and that does happen.

Eustacia: Yes, I think that's why I wanted to keep the recording of this is strictly for us and a way for any of us to refer to it again. The advantage, I think, of a telephone call is, it's the last privacy that I know of and we have to talk about the effect of violence and where do the dads fit into that.

Tom: It's very easy to go hide in work and I have positively did that from time to time. And I could just bury myself very easily in work and just not do my part with Eric or with Deb.

THE ROLE OF DAD

Rob: But it sounds like you have done a job, Tom.

Tom: Well, not all of the time. At time to time I do pretty good, but other times...

Rob: You have been pretty involved from that little bio I read.

Eustacia: Yes, that was my reaction.

Rob: Again, it's a very male thing to hide in our work.

Rich: Maybe (being the devil's advocate for the dads), it's also what we know how to do to contribute. And so if we are at a loss for how to help and we don't really know how to help, 'I'll work harder' cause that way I'll produce more income or give more to the family that way, because that's what I know.

Eustacia: Is this Rich Weinfeld?

Rich: It is Rich, yes.

Eustacia: Just trying to make sure I was identifying the voices. I think this brings up something that I keep running into and that is that men want to fix things

Rich: Absolutely.

Eustacia: And women...this isn't going to get fixed.

Rob: But it's not that women don't want it fixed..

Eustacia: Well...

Rob: Women are better caretakers.

Eustacia: Well, they don't discuss it with the intention of thinking they can fix it tomorrow.

Rich: Right

Eustacia: They discuss it to bring the situation to light, I think.

Rob: Yes, and I think what Rich is getting at, a little, and I agree with it, I think that the guidance we can give is to help men understand what they can do.

Rich: Right

Rob: They know what they can't do. Fix it. They know what they can't do. Talk freely about it. But what can they do and I think that is where we can make a difference.

Eustacia: What I keep looking for is how these boys coming along need a dad to teach them how to be a man. And we women can't do that.

Rob: Well, I certainly see that. When the boys on the spectrum become teenagers, they long for their dads. They want to spend more time with their dads.

Eustacia: But

Rob: They are a very different kind of man than their dad imagined. That's not easy for fathers.

Tom: Eric very much enjoys his time with me and I tell myself to spend more time taking him, you know, with me because he thoroughly enjoys that.

Rob: Does he ride the tractor with you Tom?

Tom: He did for a while but he becomes very bored very soon and now as he has gotten bigger it's very difficult to get him in and out of large equipment.

Rob: I see

Tom: So, not very often because it's so hard to get him in and out. There are ladders and all that. He does some but not much anymore. When I could carry him up the steps, it was great but I can't carry him now he weighs almost as much as me. There are limitations too ... you have to kind of overcome some of those. Another thing we try to do more is travel. And Eric enjoys that and that's my time with him because that's just Deb and I and Eric so we travel and we spend that whole time together. But that's ...

Eustacia: Well, that gives him a sense of the world. That seems to me, valuable.

Tom: You know when we travel, one thing we found when our interaction with other people. Eric knows right away instinctively if people are comfortable with him. Because he will reach out and take someone's hand sometimes and we go, "Oh my" and they say, "Oh no, that's fine" and he can very much tell, even when we can't, if they are comfortable around him or not. That's just a funny thing we noticed very much the last couple of years. We were at [a place where] a band was playing and it was getting near the end. The couple sitting by us stood up to leave and Eric stood up and took the women's hand and she just laughed. I guess he was set to go. Back on other things, you asked me about riding the tractor and I said not very much because it is so difficult to get him in and out. I have to look back and say that there probably is a way to have him ride more if I really wanted too.

Eustacia: Well, you have to evaluate it, don't you, a little bit on if he is going to get bored, going to be uneasy and it doesn't work?

Tom: Right – short times are very valuable but it's very easy just not to up and do it because it takes time and it's inconvenient and on and on, "Well I really can't do it so I won't." Well, if I can't do it great then I won't do it at all. Does that sound correct?

Rob: I think that does sound familiar and it sounds male.

DADS AND THE CHILD'S FUTURE

Eustacia: Here is another thing I am running into in meetings. When you can no longer care for him, what will be the story?

Tom: I don't know. We have different options that are open. What we thought would happen 5 years ago or 10 years ago is not what I think will happen now. So, we are kind of in an acceptance stage of let's deal with it when it happens. Some things you can't entirely [plan for] ... it's a changing world with Eric. What his needs will be, I don't know.

Eustacia: Well, it's a changing world with all of us, I think. The whole internet/iPad world is moving very fast. Is he interested at all in the computer world? Is he able to take that in?

Tom: Just very mild games that interact. He can use a mouse and what not. Not enough to really use the computer.

Eustacia: So that's not an issue.

Tom: We thought for a while that one of our other kids may want to watch over him. But I am not sure they are ready for it now. Maybe someday they will be. It's a huge challenge. I wouldn't want to impose it on someone who really didn't want it.

Eustacia: Yes, that's a hard one. Rich, you're very silent. What's your take on this ...

WHAT DADS WANT

Rich: Well, I think my biggest experience with this topic - I certainly work with kids on the spectrum and written about kids with high functioning autism- but where I find myself going tonight, thinking about this topic is – I've done some leading of men's groups, so I am thinking a lot about how/what would work to get men to be involved and be comfortable and to want to stay involved. I just jotted down a little list for myself thinking about this call, just some of the things: What do men want? They want to be in charge. They want to be effective. They want to know the answers. They want to ask questions without looking vulnerable. Get advice without feeling talked down to. And they also don't want to have to deal with too much emotionality. It tends to be overwhelming to deal with too much emotionality. So, what would work, -and I know Robert, you are already doing this, so you can speak to what really works. Mine [My advice] is more theoretical based on men's groups, not on the topic of autism, but it seems to me knowing what their goal was...having some information about how to "fix" the problems using that fix in quotations and then being able to see progress. Fixing the problem doesn't mean curing autism, but fixing the problem might be getting your child to interact more socially or to behave more appropriately in public or whatever small goals you have and to get some strategies for doing those and being able to have a way of really seeing that what they as dads were doing was having a positive effect.

Eustacia: I always said about Temple – she isn't cured of autism but she is fulfilled and she is fulfilled as she would like to be fulfilled. And I hear what you are saying because that is the goal.

Rob: I concur with what you are saying, Rich. I think there is a lot of emotion in this but what guys want is 'what can I do?' 'How can I be a better father?' And we can't be the hero and save everybody, but in a way, in the stuff that you're talking about. There is this concept in male psychology that a man can become a relational hero, can improve his relationships. That we can do. So, if you can improve the relationship with the child with autism, you are strengthening the family. If we can help guys do that, we are doing a lot for them.

Rich: Right, right and I think going back to what you said in the beginning -about that they are going to come because the significant female in their life is going to make them come- at least [a place] to start. I think also it would be important for them to know whether they are coming to something that is designed with the way guys learn and what guys need in order to progress in mind(?). They are coming to a male centered or male bias kind of program. I think that is an important thing.

Rob: Yes, I agree. One of the things on Saturday, one of the things I said at the beginning, which I often say something like this – I said, the goal of this isn't to - I know this is hard for guys to talk - but the goal of this is not for you to be more like women. The goal of this is to be a better man and a better father.

Tom: That's perfect.

Rob: And they respond to that – like 'okay, so tell us more.' And then you can talk about some of the feeling stuff as it fits. But the focus is on, ok, how do we handle this better?

Tom: Right

Rob: But they know it's tough to handle and they want to handle it better. I approach families in general and fathers included that way.

Eustacia: I can only tell you as a woman, we don't want our men to be like us. We want that male response and it seems to be sometimes it gets distorted when the man removes himself from the problem and the couple finds themselves living parallel with each other.

Rob: Parallel lives

Eustacia: Then what happens is that women sort of take on the male role and say, "Well, that's alright I'll sort of butch my way through this." Then, we lose their femininity. Then, the men don't find us very appealing in that mode because it throws off their masculinity so they are going to go searching for a woman who fills that void. And I see that combination of what happens between a man and a woman matters a lot and I am glad to hear what you are saying about helping them to be a better man.

Rich: One of the studies that I read and sent out last night. The fathers were trained how to do the intervention and then they had the role of how to train the moms in how to do the intervention. I thought that was so brilliant.

Eustacia: What do you mean by intervention?

Rich: Something in working with the children. Fathers were taught how to do something new to improve the interaction of the children.

Eustacia: Oh, it's like early intervention.

Rich: Yes

Eustacia: Oh, I just needed to define the word.

Rich: And then their role was to teach the moms how to do it. So, again it was very much playing into the male need to be knowledgeable, authoritative and in charge. , I think that is such an important thing to keep in mind.

Rob: Yes, because they are getting all the information from their wives and significant others who are also getting it mostly from female therapist so they are in this female dominated world and to get something direct that they can transmit is more empowering. And they can get it from a woman but ...

ACTION ORIENTED TALKING

Eustacia: But they don't, Rob. I think one of the things that trouble me is these young psychologist are the same age as the young men and they are not going to talk to this woman.

Rob: Well, true Eustacia but there are far fewer men in the field. Actually, one of the things I try to do is teach women how to talk to men - which is a more action oriented way of talking.

Tom: Rob, give an example of that.

Rob: Well, as opposed to say, "How do you feel?" say, "Let's talk about an action plan".

Tom: That's great.

Rob: Then you engage the guy and the feelings will come out. Like, tell me your story, tell me what you want to improve and the feelings will come out but they will come out in a different way. In the story, not like I

feel ashamed. A guy is not going to say that. Now, is there shame there like you wrote about Eustacia, absolutely.

Eustacia: Well, I wrote this right after Dixon, Tom. That's what brought that out and I'm apt to read it at a conference and I am amazed at the men that come up to me in tears. And I thought, I've hit a raw nerve without half knowing what I am talking about.

Rob: Yes, well, I think you knew Eustacia.

Eustacia: I guess did because otherwise I wouldn't have gotten that reaction. But, I like your idea of giving them an active plan.

Rich: Well, it's so interesting. Even tonight, in the first 5-10 minutes of the conversation, I'm thinking to myself instinctively, are we just going to talk or are we going to come up with some kind of plan.

Eustacia: I agree. My thought behind getting you all together was that if we pooled our thinking together. That was the reason for recording it, so we could all listen to it. We can write it, I can write it up. You can write it up. We can each write it up and we can put this together and then we have a piece of writing that we can each put onto our websites or use in whatever way is valuable to us. I would like to get credit to the Temple Grandin Eustacia Cutler Autism Fund because that establishes us. What I am after, I'm not trying to raise money but I am trying to create some insight. And that is what we are talking about right now. I don't see a lot of it. I see money being raised to get somebody else to do the job for you. And that doesn't seem to me...

FEELING IN ADEQUATE

Tom: We sometimes as men,

Eustacia: Can you speak up for me Tom I don't hear that well.

Tom: Yes, same here. (laughter) We sometimes feel inadequate at what we're trying to do and that's compounded sometimes by what we do, [because] we don't do [it] very well. So, from the beginning we feel inadequate and then stumble in trying to do what's good. We are really then set back. Does that make sense?

Everyone agrees

Eustacia: But I think that is true of women too. I think back at myself and realize what a ding-a-ling I was and how much I hid because it was the only way I could figure to get through it was to hide things, including from myself. And I just had to stumble...we are all stumbling.

Rich: I do think, Eustacia, that, of course, when we talk about genders we are always in danger of over stereotyping, but I'll go ahead and do it. I think if you read the literature on boys you'll see that shame is something that hits boys even harder than it hits girls. We are intrinsically wired to...we have to know what to do. We have to be able to perform. Maybe it's not just wired, maybe it's also socialized but when we are in the face of our wife or girlfriend and she is coming to us and doesn't know what to do and we don't know what to do either, it's overwhelming. I think we can get into this fight or flight mode which flight is spending more time away from home and spending more time at work and the fight is all the marriages and relationships that break up.

INSIGHT AND PLANS

Eustacia: Yes, that is what is troubling me is the huge rate of divorce. And that by putting together, if people know to go look to a site, (just to follow through why are we doing this now), if there's a site that's insightful. If insightful blogs turn up on your blog, I know that would have helped me when I was young. I would have loved to have been able to do that.

Rich: Going back to what Robert said before about action talk - about a plan. I think it be great if we had the outcome of a few steps, maybe tips for women in talking to their male partners about how to get them more involved. What are some tricks? Are there others that occur to you Robert that really work?

Rob: Yes, I've written a few little things about that. I could certainly share with everybody soon. My new book has some of that. I have written some blogs about that and Rich from what you are saying I think you easily connect with it and you could probably add to it and help refine it. That would all be a part of it. I think the advantage of doing this through TGEC Foundation is that gives it a lot of visibility and credibility. So, there are so many website and so much stuff people are overwhelmed with it but the credibility of...

Eustacia: It seems to me that what we want is an autism GPS.

Rob: That's a great concept.

Eustacia: That's what I am after.

HELPING DADS HELP

Tom: Could I add just one thing that I wanted to say. Women, tend to need help on how to help their husband. That's very important. Sometimes, a husband is trying to learn how to do certain things will come across wrong and response from the wife/girlfriend, whatever, is you know I'm here every day, I deal with this and here you're here just now and then and you trying to tell me how to do it so they need help too.

Rich: One of the studies that I read actually talked about kind of the potential for this backfiring and that when women were used to being in charge of the child of autism and as men entered into making decision or giving opinions, the women reported more stress. Because it's counterintuitive...

Eustacia: That I can understand because we have been dealing everyday so the chances are we will deal more easily and the child will react to us more easily. Now, somebody else coming into the picture you have the double stress of the child and the ineptitude of the dad entering this scene.

Rob: And it's hard to let go

Eustacia: It's hard to let go and it's hard to watch them do it wrong. Everybody's nervous then.

Rob: That's true with parents of typical kids too. That a lot of caretaking falls to the mom and it's hard to let go and it's sometimes hard for the man to have room in there. And yet, particularly with autism, that becomes even harder on the woman.

Eustacia: I see also entering the picture the fact that it now takes 2 incomes in a family and that we women have entered, not that we weren't always in the workforce, but we have entered the important workforce so the dynamics have shifted there. I see that in a big city like New York.

Rob: Yes, but the woman is still the primary caretaker so she is still overwhelmed and probably doing most of the case management type of stuff and most of the hands on meetings, and she's missing more work time and that's the kind of stuff I hear.

Eustacia: Yes, I think you're probably right.

Rob: Even though the world's changed.

Eustacia: It hasn't changed that much.

Rob: No, no. And male infants are more responsive at birth but in the first months of life, parents stop comforting the male infant to the degree that they will comfort the female baby. So the boys are being taught to suck it up, even in the modern world.

IDENTITY OF PARENT AND CHILD

Eustacia: You know all that we are talking about is all about identity. Who it is we think we are and how we carry that out. Tom, I think you have great courage. You have carried out a difficult task.

Tom: We are very lucky to have Eric in our life. He has really taught us a great deal, just a great deal. You know. One of the things my wife and I have spoken about is that Eric was born disabled, at least from age 1, he was very disabled. And what would it be like or how much more difficult would it have been for us if say he were a normal child up until the age of 12 and because of an illness or an accident or what not, he became very disabled. How much more difficult, I guess, that would be to deal with for us. I don't know, maybe, but we have only known Eric as being disabled. Does that make sense...

Eustacia: You are bringing up what happens in families when schizophrenia sets in in the teens. There has always been talk about autism and schizophrenia being linked – one coming when the child is very young the other turning up at adolescents. Yes, I think of a friend of mine whose son turned schizophrenic in his early teens. And it was heartbreaking. He had been this enchanting boy and suddenly the boy is gone.

Rob: And late diagnosis of autism feels like that to people, to some extent, when it [autism] is more subtle and diagnosed late. But I think what Tom is bringing up is also something that would be good in terms of the autism GPS. What are the children teaching us? What are they teaching moms, dads, therapists and that can guide us.

Eustacia: I like that.

Rob: We are changing as people. Our identities are changing.

Eustacia: Yes, we are growing along with the children.

Rob: And that's a good thing - that aspect. There's plenty that's hard.

Eustacia: I'm just writing that down. I like that, yes. Yes, I've always had a sense that Temple and I had to grow along both of us. And I still see it happening today.

Tom: We go to Children's Hospital twice a year to see a neurologist in Chicago. One year, a number of years ago, we went in there and we were talking to Dr. Stack. One of the questions that we posed, because Deb and I had been thinking about and the question was, 'What would Eric achieve in life?' 'What could we expect long term?' 'What could we hope for?' So we posed that question to Dr. Stack and she said, 'You know, it's not if we [you] would ask that question, it was when.' She said, 'Every parent that I deal with, at some point, reaches that.' And she said, 'You are very lucky and I could show you this by taking you for a tour of this hospital. And when we completed the tour you would consider yourself very lucky.' So, I mean that's just a little different perspective. But no matter what our challenges are, they at times not near as great as what others face and that sometimes is helpful too. Does that make sense?

Rob: Yes. Well, it's a strange thing about human nature we feel better when we see somebody worse off.

Eustacia: I feel somehow that all of them have paid the price for us. And I feel grateful for that. I remember when I studied severe retardation and had to look at [children with severe disabilities] that can't function at all and I found it very... I was upset until I began to think that they paid the price for us and we must therefore take very good care of them and do the very best we can for them.

Tom: My mother always told Deb and I, God never gives us anything that we cannot deal with. So, I don't know if that's true or not, but.

Eustacia: I don't know I like better what you said about its intermittent. We do it pretty well sometimes and sometimes we don't do it very well

A DADS GPS

Rich: I am thinking about the autism GPS, which I really love, in terms of men that we don't want to ask directions but we do love GPS's.

Laughter.

Rob: Right, that's great, that's great

Eustacia: That's like that old joke about why does it take so many sperm to fertilize and egg – because none of them ever stop to ask for directions.

Rob: So what we are getting at here is the language that men can respond to. Which isn't, "How do you guys feel?" That's not a conversation starter.

Rich: Robert, one of the little tricks that I aim to use at our men's group that ended up working incredibly well was ... - In the beginning, we would go around and ask men to talk about what was going on and there was a lot of resistance -. Then, we moved to, [where] we would come in, [and] we would all anonymously fill out an index card with a question that was bothering us or something we needed advice on. We put the cards in the middle and pass them out and everyone, one at a time, would read a question that they had - which wasn't necessarily their question - and the other people would give advice and it worked because all

men wanted to give advice and tell [others] what to do and nobody wanted to be identified as the person who needed advice. So, I felt that there was something in there that really worked.

Rob: Yes, to be anonymous, to be able to ask something that you might be embarrassed to ask.

Eustacia: Or even say something that you know isn't going to be the proper thing to say but to be able to get at it

Rich: And to be able to listen to other men tell you what to do but they are not tell you directly what to do because they don't know who you are.

Eustacia: It takes it away from the realm of accusation, or shame or scolding.

Tom: How many times have we sat in a group and somebody asked a question that we were dying to ask but were too embarrassed to ask it.

Rich: Maybe that could be a feature of the men's GPS – people will be told to ask their questions anonymously.

TELLING YOUR STORY

Eustacia: Yes, I think I like... that's nice. I think sometimes, people, maybe it's a female characteristic, like to tell their story. Don't you find this Rob? After a presentation, people come up and want to tell you their story.

Rob: Oh yes, men too. Women are just more talkative but when men start talking they want to tell their story.

Rich: I agree.

SCHOOLS

Eustacia: It's like all the great journey stories in literature. Where they finally find their way home are identity stories. It took me a long time to realize that when I was young and read these tales of wandering. But people finally come home and home is being comfortable I guess with yourself and feeling whole within yourself. Well, now, what else did I have down here because we have some more minutes. We have covered a lot in $\frac{3}{4}$ of an hour. I could read these questions better if I turned the light on. I know Tom it's still light where you are but it's getting dark where we are.

Yes, it was a question of, I know what it was, this is for you Rich, about the schools. I got this from one teacher. Again she said it privately, she didn't want anyone else to hear it. She said that the other teachers were treating children differently in the school depending upon on the rank of the parents. If the parents had a social position in the community the children got better treatment. Now, do you find that true?

Rich: The short answer would be yes. I don't think of it as social rank so much as – 'Am I [the teacher] going to be visible in what I am doing?' 'Am I going to be called to task for what I am doing?' 'Are these parents going to question me or really know about what's going on.' Yes, I think those kids get more attention.

Eustacia: You think it's true then what she was saying?

Rich: Yes.

Eustacia: I don't know if she used the word 'socially' because she kind of rolled her eyes when she told me this tale. But I think you are right they [the parents] are going to make the teacher be more accountable.

Rich: Yes, I think there is..

Eustacia: But this brings up something that I'm worrying about with the teaching because I don't like that word special. I also see parents who feel that their children's poetry is extraordinary, their painting is extraordinary, their singing is extraordinary and you read the poem, and you think, well no, it's really not very good, if the truth be known. You [the parents] are preparing your son in life to be a poet where the published poets in this country have to take on other jobs to support themselves because. even if you are Keats, you can't make money on poetry. And the child has been told, (who is now no longer a child), "Yes, you are wonderful. Anything you try for - you're going to get there." And I have heard this from parents that are holding teachers accountable.

Rich: One thing in my group, (in a way we are guilty because we advocate on behalf of parents for their children) we shine a spotlight on an individual child and very often that does get the child more attention, more services, more interventions. But we feel it's very important not to do it based on which people can afford the service, another way of saying, maybe the social status. [This is] a way to give it to all the parents.

Eustacia: Even distribution. Well, I agree with that and I am thinking of one particular mother where I thought (who had ludicrous dreams for her child) that puts the teacher on the spot.

Rich: Well, it's a balancing act, I think. We want to identify the gifts of every child and dream big for every child and hold teachers accountable for helping every child to go as far as they can. But there is also a flip side to that of how to be realistic about that. [We must know] how to also hold the child accountable and not just everybody in the child's world accountable. It is a balancing act.

Eustacia: A balance. Yes, because I felt the mother was not being fair to the head of the school because I was there when she talked. I said I think the school is handling this very well and she would have none of it.

Tom: I just want to interject, as a school board member for 20 years and a special ed board member for a number of years, there is no doubt that my son was treated differently. My wife and I never asked for any services that were not warranted or reasonable but I think the staff, in fact, felt that they needed to be more accountable.

Rob: Sure, they knew who you were and they knew who your child was.

Eustacia: I think that's good. This is what neighbors do for each other. The neighbors helped me with Temple and the school helped. They included her in the neighborhood and sometimes that's not easy.

Rob: Right, but when it can happen, that is great and that's the advantage of some level of inclusion in the neighborhood school.

INCLUSION

Eustacia: Well, that's the other thing. Rich, you working in the education area, - and Tom. How do we accomplish more inclusion. How is the child going to learn to be part of the mainstream if they are not being schooled in the mainstream?

Rich: Well, that's a very big and very interesting topic to me because I certainly believe in inclusion. but what's been happening - that I see over the past decade or so as - [is] we have hit hard economic times. A lot of people have been preaching inclusion but not putting in the right kinds of support and resource to make it work and so inclusion has almost become a name for not doing anything. I totally, totally believe in doing inclusion but it's just as intensive and expensive, if not more so, than pulling a child out. And that we have to make sure that it is being done effectively.

Eustacia: Not so easy.

Rich: Not so easy is right. It requires training. Training for the classroom teacher, and then supports for the classroom teacher where they feel like it is happening in the current environment.

Eustacia: Is there any kind of course for the everyday teacher on the subject of autism? Which is certainly now a popular subject.

Rich: I think there are many courses.

Eustacia: Do they take them? Do the schools require them? Is there any specific overall teaching...

Rob: I don't think there is any certification in autism but most universities are starting to have courses in it.

Rich: I think you find teachers getting a course in special ed which is a huge topic and as Robert said, not enough specifics on the different disabilities or on specifics of autism. We teach a course based on our book School Success for Kids with Asperger Syndrome. We do 4 day workshops and a lot of different formats for it. But it's a drop in the bucket for all teachers who could benefit from learning more about these kids. [Kids] who now, -going back to the inclusion piece,- they [the classroom teachers] are getting more responsibility for being the one educator for all kinds of different kids. And they [the classroom teachers] really don't have the training to do it effectively.

Tom: In the[se] economic times in the school, at least here, classroom sizes are growing and special ed services are being reduced. So what's happens is that high needs kids are being placed in an already overcrowded room which does not do much more than breed animosity from staff and other parents who now realize that their kids are going to get even less attention. So it's a very poor scenario all the way around.

Rich: I agree and I think if you ask the principal/superintendent. they would defend it talking about inclusion. That's kind of what I was getting at earlier. Don't get me wrong, I'm not saying inclusion is a bad thing. Inclusion is being described as a cover for lack of resources and more and more students being placed in the regular classroom with the general ed [education] teacher being responsible.

Rob: So, I think when we are talking about schools this is certainly something that is going to come up as we get this GPS moving.

A FAMILY FOCUS

Eustacia: I think so. We are going to have to separate out topics, I think. Don't you?

Rob: Yes, and this is a big topic that everybody covers. Well, not everybody but plenty of people cover.

Eustacia: Yes they do.

Rob: But a true focus on families, not too many places are really working on that

Eustacia: It's family focus that I am after. No, they are not. They give lip service to it...

Rob: See that's what would make this stand out that it's a family focus and we might offer some insight as how to approach educational issues, but not...

Eustacia: Well, the best insight that I have heard is from Chris Curry is to advise all parents to never go to an IEP without an ally and never to sign anything just say, well this is very interesting, I'll take it home and think about it.

Rich: Yes, I like what you are both saying. If our approach was from the family perspective - what do you as parents, what are your responsibilities in terms of advocating for your child in school. But [we would] not get into what do the schools need to do differently. I think that's a wise way to approach it.

Rob: Yes, like tips for coping.

Rich: Coping and advocating, we don't want them to just deal with it but what can you as a parent be a change agent in your child's school program.

Tom: There is one quote that I heard tonight that sticks very strongly with me and it was that men hate to ask for directions but love to use a GPS. Now, if we could keep that focus in mind and have a resource out there like that, it's a home run.

Rob: That's a conversation starter

Eustacia: That's a great way to start it.

Tom: I love that

Eustacia: Well, maybe that brings us to a close. I think we have done our hour and thank you all very much. This is invaluable.

Rich: It's a pleasure Eustacia and nice meeting you guys.

Eustacia: Nice to meet you and we will meet again.

Rob: I just want to add Thank you Eustacia for being the catalyst and the glue and bringing us all together. It was very meaningful.

Eustacia: Thank you. I have learned a great deal in this hour and I am grateful to you all.