

Note from Thomas: Here is an article, published in Volume 15, issue 4 of *Focus on Autism and Other Developmental Disabilities*, circa November, 2000. I am in italics, Theresa is in normal print.

A Look at One Relationship

by *Thomas A. McKean* and Theresa A. Vincent

Relationships are hard work. And you certainly don't have to be autistic for this to be true.

I met Theresa in, of all places to meet someone, an America Online chat room. However, this particular chat room was parents supporting other parents of children with autism. There was the occasional bad apple that would pop in every now and again but for the most part it was very helpful to those who attended. Theresa lived in Virginia and one day her work brought her to Ohio where we met. As it was my 34th birthday, she brought me a bear that I have been sleeping with ever since.

Theresa is a challenge with three kids from a previous marriage (two with autism: one diagnosed before we met and one after) and I am sure I am a challenge with autism. I am not sure I care to know which of us is more of a challenge. I don't think it really matters.

I had been in relationships before. Two of them were serious. They didn't work out and I was at the point in my life where I had just about given up. I had seen autistic friends of mine get married and get divorced. I didn't want that to happen to me. Was I really ready to try again? It was to try again or be sad and lonely all my life. I knew I didn't want to be sad and lonely, so I decided to try again.

Problems on both sides immediately appeared. Her insecurities and my sensory problems made the relationship difficult.

When I first met Thomas I was just coming out of a divorce. It was a difficult marriage, having an autistic child makes any marriage more challenging. I had heard of Thomas McKean and his writing before I had actually met him on-line. It was a time of searching for me since my youngest son was showing some strong autistic traits as well. I was primarily searching for answers but what I found was a good friend. Thomas was compassionate and understanding of everything I was going through. He was the person I would call when that IEP did not quite go right, he was the person I could cry on when things were becoming out of control.

We decided to make a go of it. My trust issues were a big concern to him and his sensory issues were a huge concern for me. We started talking more on the phone there were many nights we would talk until 4:00am and Thomas always had a way to make me laugh. Thomas's charm and wit and continued compassion were some of the few reasons I fell in love with him. We lived about seven hours away and we did get to visit often, I remember the first time I went to visit having business in Ohio I met with Thomas on his birthday. I think we both knew how special our relationship would be then, but our insecurities held us back and it was several months later before we said we would try to date.

Theresa seemed different than the others. She had an understanding about her that I found very hard to resist. She not only tried but was able to relate to me in a way no one had before. How could I not love her?

We have now been dating for several months our commitment and love for one another is strong, however there have been continued problems. Many couples have little disagreements and concerns especially when first dating, ours seemed to be amplified due to problems associated with autism. I felt like this is great now I have autism times three in my life. Thomas is moving to Bedford to be with me and the kids and I have supported him in that decision. He has had the desire to leave Ohio for quite some time and my little town seems to be ideal for him. The fact that I am here helps to. I am excited for his move and I have made the commitment as he has to make this relationship work, there are some days I have doubts though as I am sure we all do about people we get involved with. I am also very much aware that the move will be very difficult for Thomas a transition that will pose its problems on everyone, I am proud of him for this decision and it shows me how much he is willing to make it work for us. Ordinary people would be in the boat that says its not big deal for me to move by the people I love, but I know for Thomas it is a strong challenge to move to be with us.

It is true I have wanted to leave Ohio for quite some time. Aside from a few close friends, there is nothing keeping me there. Columbus is not a very pretty place, nor is it very friendly. Having done a lot of traveling the past several years, I have seen that there are places far, far better to live than Columbus.

Bedford is a wonderful place. When you walk outside in Columbus, you see the freeway. When you walk outside in Bedford, you see mountains. When you walk down the street in Columbus, people go out of their way to avoid you. When you walk down the street in Bedford, people stop and say hello. No one is moving at

warp speed in Bedford like they are in Columbus. The saddest part of people moving so fast in the big cities is that while they are moving fast, they really don't know where they are going.

I have made several friends here in Bedford already. While it is frightening to leave a place you have called home for 34 years, it is also exciting to be starting over.

There are many problems we face as a couple that "typical" relationships I am sure do not encounter. The biggest problem in our relationship comes from sensory issues I believe. The second time I met with Thomas I kissed him on the neck to say HI to him he pushed me away and said it hurt. During that trip I was also a little sweaty from the long drive and it was warm again I got pushed away and told to take a shower and then he would hug me. Warning bells went off, I was thinking to myself I just drove five hours to see you and you are pushing me away for kissing you. Well, I am finding out that is only the tip of the iceberg. The tactile issues are so severe at times intimacy seems like an impossible task some days. I need to always remember and sometimes it is hard to not take it personally that Thomas needs to be touched in a certain manner so as not to cause him to be in pain. I believe we all have ways that we prefer to be touched over others. Thomas has to have deep pressure I cannot go up to him and caress his arm or hand I have to go give him a bear hug or rub his arm rather than the simple caress that I prefer. Touch on certain areas of his body are a cause for pain, on his neck and face touch is enough to cause him to cringe as it physically hurts him. Thomas has been great about telling me what he does prefer and what brings him pleasure. I was very hurt on how rough he would push me away so he does still cringe but now he says it tickles and in a more gentle tone. He shows me what touch is pleasing to him and how to do it. I on the other hand show him that I don't like a strong touch but I prefer a light gentle one, I also know that this is difficult for him at times but he gets a ten for effort. With good communication this is an area in our life that has improved a great deal. I must say this about Thomas and I cannot say it enough he is ALWAYS willing to try. His effort to make our relationship work has been worth it all even on those tough days.

One of the things I find most difficult in our relationship is Theresa's occasional tendency to get upset over being on time. A good example of this is sometimes in the morning she will tell us all to hurry up if we have to be somewhere. I have to keep reminding myself that it is nothing personal and that she just wants to be on time. This can be hard for me because I have a way of taking these things personally.

Her kids can be a challenge for me, too. I am in the very awkward position of not knowing how far to go or not to go to have fun or to discipline. Theresa changes her mind about this constantly. I am sure as the relationship goes on it will settle into a routine regarding those issues but for right now I am not sure what to do. A lot of times I come to her for help with the kids. Sometimes she tells me it was the right thing to do and sometimes she gets mad at me that I don't handle what ever the problem was myself. This is something I find to be very confusing.

Another hurdle that we continue to try to tackle is our differences in motivation styles. I get up at 5:30 and go all day until I pass out again around 11:30. With three children being a single parent taking graduate courses and working part time as well as all the boards and volunteer work I am up all day and running. I enjoy this I like to keep busy. Thomas will go to bed leisurely around 2:00am and get up around 1:00pm the next day or so. We discussed this for quite some time because when Thomas comes to visit me I want him to join me in some of my activities, so we finally agreed on a solution there as well. Thomas said he had "balls" he could juggle in a day, he explained what could cause him to lose a ball such as going to a meeting with me but that playing Frisbee with JR maybe he could gain one back. He would communicate when too many balls were being juggled and that he was over stimulated. I know after being with Thomas for so long now when he feels its too much he clings to me and constantly wants deep pressure especially through being hugged. I look for these external clues as well as his verbal ones I am learning to join him in his circle and what his needs are, when I manage to do this Thomas is much more relaxed and therefore I am as well.

The same can be said of me. When she is happy, I am happy. I love to see her smile. It makes my day brighter.

Theresa has to remember that I have lived on my own for a very long time. And now here I am trying to fit in with a family of sorts. No one can do this overnight, autistic or otherwise. The past three years of my life have been filled with nothing but conference appearances because I have been very depressed. I find I am not so depressed when I am with her but now I have the problem of figuring how to fit in and join a family unit as opposed to being on my own.

The nice thing about living alone is you can do what you want when you want to do it. I have found this is not so in Bedford. Even something so simple as checking E-mail is a challenge when the kids want your attention. You have to learn to balance your own needs and desires with those of the children you are helping to raise. This is not an easy thing to do, but I am trying to learn because I have felt a sense of accomplishment when I get it right.

There is also a problem of sensory overload that is evident in autism. With three kids, this happens to me more than she thinks it does. I think it happens to her more than she thinks it does. We are still working on how to deal with this and it has led to many arguments. But one thing I can say about Theresa is that we always make up.

As Thanksgiving is almost here we have found another issue that is becoming more apparent to us. Socialization, Thomas is terrified about going over to my parents for Thanksgiving this caused a huge disagreement between us. I have felt that you need to spend holidays with your family and it is a time for celebration. Thomas informed me a few days before the holidays that he did not like them and he would prefer to stay at home while we went to my families for dinner. I am well aware of the anxiety Thomas would have to go through to attend holidays with others but I offered some compromises such as a room he could escape to that had a VCR and TV in it as well as a bed so that he could have some down time. This still is causing some stress between us and making me realize that there are many things that will not be "typical" in our lives. Thomas is going to try maybe he can bring his car so that if it gets to be too much he can go home, but again his willingness to try has been a strength for us.

Our lives will never be "typical," there can be no doubt about that. That can be said to make it more exciting though. Never a boring moment with Theresa. Not like there was when I was alone. It is no secret to those who know me that I don't like holidays. I can be bribed to do Christmas, and I usually am bribed by these things called, "presents," but other than that, I'd be happy leaving the holidays alone because all they do for me is remind me how different I am and I can surely do without that. Thus, spending a holiday with a family that I don't even know is not something that I find to be comfortable. Spending a holiday with a family I do know isn't comfortable, either. We all muddle through these things we don't like for other people, I guess. The sacrifices of love. Looking at it objectively, how bad can it be?

There are many issues on both sides of the fence I know for Thomas issues such as my three children and my trust and anxiety issues about going into another relationship are a concern to him. Thomas has been great with the kids there have been many times where he comes to me and asks what to do in a certain situation, and there are times I have had to interrupt and mention different ways he could have handled a problem that arose. I have felt once again our communication skills have gotten us through a lot of these obstacles and when it does become to much for Thomas that he always has an escape route

somewhere he can go to take a break away from everything. There is something to be said about having autistic children the environment is very conducive to any child or adult that falls into that spectrum I am aware of the surroundings not becoming to overstimulating and how to handle behavior issues as they arise. I feel like I am an expert in sensory integration methods. Thomas brings wonderful insight and a tremendous source of encouragement to me and the kids. There are many positive things in our relationship and this is one of them that he continues to help and understand the kids like I know no one else can.

Theresa's trust and anxiety issues are very hard for me. She likes to compare me to her previous relationship and she wonders if I will hurt her. I tell her I love her and she thinks I am making it up. That really hurts me sometimes. I have no intention of hurting her because I love her. She has suggested that we go to therapy sessions together as a couple. While most men would reject this idea, I actually welcome it as it will give the relationship a better chance to succeed. If I am going to move from where I have lived all my life to someplace I have not lived before, I want, even need, all the help I can get for this relationship to succeed.

Theresa has shown me that I have knowledge of myself I didn't know was there. She has shown me that I am stronger than I think I am. She has shown me that I do have talents that have been going to waste the past few years in that apartment. She motivates me to move forward. One small and slow step at a time.

There are many ways I have adapted to make Thomas's "world" a little better. Thomas is disorganized tends to forget where he puts very important things like his medication or his sunglasses. Thomas hates bright sunlight so I always make sure to have his sunglasses ready for him if we are heading out I put them in my purse when we go in somewhere so they are ready before we go out into the sun again, again this is something that causes him to be physically sick so I try to manage to make him more comfortable. I know those things that can help him regain his "balls" so that he is more able to cope with his day I know big hugs and deep pressure are a way for him to stay focused into his current environment.

There are many ways I have adapted to make Theresa's "world" a little better. The main thing I have done is take on a father figure role for the children. Especially the older two. I play with them, feed them, put them to bed, I watched them for her while she is away without asking compensation. The oldest, JR, is very easy to like. I can go to a toy store and get a toy that I like and he will like it,

too. Amy will start out being afraid but she will eventually join us and that makes it even more fun

I don't always like getting out of bed in the morning when I am so used to sleeping through it. Sometimes there is a Dr.'s appointment or something going on at the school that I have to be involved with. I have found with time that these things are not only okay, they are very special.

This may not be the ideal family, but it is a family that loves me. To me that is what matters. I am fortunate to have them.

As we are fortunate to have Thomas. Through all of our difficult transitions and trials we have had to experience, one thing does remain. Our love and commitment to one another has with stood all of our difficulties. It took us awhile to make that commitment stand there were many times that we wanted to walk away from it and all the problems that we knew were going to encounter and all the ones that are coming. We have handled our problems by not only communicating but by praying together. God is something we both have in common and a tool that we have used because if we did not we know that our relationship would be impossible. Thomas has been great about going to church even though the social nature of it is too much at times for him. He has a good relationship with the pastor and the church has welcomed him with open arms. Once again Thomas has shown me that he cares enough about us that he is willing to overcome his initial fear and transition problems.

One time Theresa and I were at a restaurant and I wagged a fork at a waitress and Theresa said I was flirting with her. So now I wag my fork at Theresa. It has been very hard getting to where we are and we have both walked away more than once only to get back together again. The fact that we do get back together again gives me great hope for our future.

I must also realize to not expect so much out of him. This is very hard for me to do. I forget that he is not comfortable with some things and that he would prefer certain routines and he has his own expectations, not mine. Thomas has sat down with me when it does become too much for him and reminds me of the struggles he faces and therefore they are my struggles as well. I want Thomas to fit into our home and our lives, I want him to feel like my home can be his as well. In order to do this I must put my own needs and desires aside at times, this is hard for me I want to also be as independent as possible. As I watch how hard he works I am compelled to give up things that I would rather do to please him

and make him happy. I have seen so many times Thomas do those things that I know are so hard for him. So, I also have committed to do those things that don't always make me comfortable. An example of this would be shooting rockets I do love to do this with him and the kids but after a half an hour I've had it. I have learned however that this is a way that Thomas gets his balls back and when he is happy and content I am as well.

The rockets are fun mainly because of the kids. It is really fun to see a rocket go up a thousand feet or so and to have one of the kids catch it on the way down. I also like it because it is fun for me as well. I like to do things like fire rockets and fireworks and ride the go-karts and such. I never really had a chance to do that when I was younger, so I am making up for that now. I am very glad that Theresa understands this.

Just as she must put her own needs aside sometimes, I must do that, too. The kids sometimes, many times, come first. This is by nature of having children and it is something that I am not so sure is bad, but will take some getting used to.

Our roller coaster goes up and down a lot of days. When Thomas does not seem to understand a social situation or when it becomes too much for him he tends to shut down. This is the most difficult time for me because many times I do not know how to fix it. He just runs off somewhere and I get worried, I know he needs that time but I wonder how long it will be and how can I help. He can usually shrug it off eventually, but I feel useless at those times in our lives. Thomas also can be a little impulsive and do or say those things and later realize it was not the most socially appropriate thing to do. He has been very good about apologizing during those times. He is also very good about asking and re-stating what the most "typical" thing to do in that situation would be. There have been many a time I have wanted to hide when Thomas does this. What I have learned is that Thomas really has to be taught all of those social graces. We tend to take this for granted but he has to learn what to do memorize it and then try to replicate it again in a similar situation. Thomas tends to over exaggerate it at times. The constant practice at times can get to me to.

We role play quite a bit to achieve these social graces. Thomas loves to role play to make sure he gets it right so he feels like he fits in. A neat example of this is a few months ago I mentioned to Thomas that not everything needed a verbal answer sometimes a simple gesture would do. Thomas went right to work starting to figure out what gestures were appropriate in certain situations he would ask others that were close to him was that a good gesture was that right. It was funny, but I realized what I had taken for granted this man must literally practice daily. We also role play to make sure the right terms and meanings

come out. Thomas will say almost daily lets try that conversation again to make sure he has it right. He has been very open about criticism and always willing to try out new things. Once again our saving grace has been Thomas's ability to try almost anything. He wants to make sure he fits in and feels bad when he feels that he does not.

The role playing goes both ways. I had heard that people with autism did better when they role played so I have decided to try it. Theresa has also role played. An example of this would be a recent IEP meeting for JR. We went to a restaurant and I pretended to be the bad guy. I role played some of the things I thought he might say so Theresa could practice what to say back to him. She did very well and I was proud of her. She did even better at the actual IEP meeting.

I don't think I will ever understand gestures. I have been practicing and trying to get them right but they don't really make sense to me. I watch people on TV do it and they seem so casual about it. Jason Alexander is a master of gestures. My life is complicated enough. I don't need to turn into a George Costanza to make it even more difficult

Social graces are lost on me, too. Nowadays everything must be "politically correct" and it not only drives me crazy but many others as well! Another example is when Theresa went through the toll booth. She gave the lady her money and said, "Thank you." Why would you want to thank someone for taking your money? These are the kinds of things the general population that I don't understand. Maybe I don't understand them because they don't make sense?

What Thomas does not realize at times is that I Love Him just the way he is even lacking those social graces. Thomas usual wit and charm seems to rescue him many times with other people. As well as his constant impressions of others to relieve any dry moment in conversations. Thomas is a good man with a very compassionate heart, he shows his feelings like I have seen no other man do. The movies that make me cry make him cry the sadness I feel and verbalize he feels and verbalizes. These are great traits in him that show how open and compassionate he truly is. I would not know what to do without his wonderful hand that holds mine and his hugs that make me feel like everything will be OK. He has a great saying that he uses that we worked on during one very trying time in my life he just says over and over. "Not to worry, everything is under control" and I slowly settle down and believe it and he just lightly strokes my head as he says it and I know he has taught me as much as I have taught him. He has taught me to slow down to appreciate those things that I take for granted that a long hug is worth the world stopping for a short time and it is still OK to go out and play every day.

It is hard making it work. Yet at the same time I feel a great peace when I am with her. This is something that is new to me. I like it. I'd also like to think I deserve it. She is a strong and wonderful woman. I am glad I met her. I am a better man for the journey.

Yes, we will make it work. We know the struggles that we have to face to many for me to even think about at this time. As we take one day at a time we know that it will all be worth it, all the work and all the time and energy a relationship takes. Thomas sings me a song that he has written often it is called "Always Wanted" this song goes onto explain this perfect woman and how he has always wanted her, the last verse is my favorite after explaining this perfect woman he says quietly. You are what I always wanted, it is very touching to me as many things that he does are. What he does not realize is that he is what I have always wanted, too...

Another Note from Thomas: Theresa and I are no longer together. We were on our way out of the relationship when this was written. She and I had previously written a complete book together (in this same back and forth format) that she wanted to publish that had all of this in it plus a lot more. Since the relationship wasn't working out, we condensed it into this article that was then published. We remain friends.