

INTERVIEW TRANSCRIPT (EXCERPT)

December 2016

Reporter: Noelle Evans

Interviewees: Matt and Mary Flavin [Last name changed per request of privacy]

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NOELLE: What is it that he needs?

MATT: He needs an explanation as to why things are the way they are.

MARY: Yes, and he needs more advanced work to keep his little mind busy. And he needs somebody that he can go to to blow off steam, discuss his problems get a better explanation. Which he has..

NOELLE: And here traveling, what were some of the considerations that you.. you...took into mind?

MATT: He always likes to know where we're going, what we're doing.

MARY: Sleep.

NOELLE: Like what about sleep?

MARY: Instead of going to London off the plane we went to Brighton because it's smaller, it's not as hectic, you can just get some sleep and not have so much stimuli and you can just ease into the trip.

NOELLE: Is over stimulation a...

MARY and MATT: Big problem!

MATT: We've been concerned because in the markets today because it's been so many people. If Harry was a typical 8 year old we would have probably gone to the rugby game.

MARY: would have wanted a scarf, would have wanted to participate, would have wanted a pin from Roald Dahl would have wanted to carry the letter at the Roald Dahl [exhibit]. He would have wanted to participate more fully except we don't do that.

NOELLE: And why is there the non-participation?

MARY: I have no idea.

MATT: I think it's a step back so he's not too deeply involved in the situation.

NOELLE: Emotionally?

MATT: Yeah emotionally. I think there's a fear of emotional attachment.

MARY: There's a lot of stuff going on.

NOELLE: You mean in the Roald Dahl exhibit?

MARY: Just everywhere.

MATT: Yes.

NOELLE: No matter what it is?

MARY: Not just in the world. Lot of people just block out whole swaths. You block out all these people and you only see shops. You're sitting in a room of people at a coffee shop and you're talking to one person you don't hear anything else. I believe Harry hears everything. He sees all those people he sees the lights he sees hawkers selling giant daisy faces... it's all a bit much.

NOELLE: So it's hard to differentiate?

MARY: It's hard to process. And if it's all brand new it's even harder to process.

NOELLE: So at home, how is it that you managed – I mean understanding Harry and of course loving Harry, how have you worked with him, being who he is and who you are?

MATT: It's a mixture of catering to his personality, and trying to pull that personality out a bit

MARY: And then not catering to it.

MATT: And not catering to it because society's going to be tough on him if... when it comes down to it.

NOELLE: So how do you know when to cater and when to not?

MATT: You push until there's a terrible emotional response sometimes and then you say that's too far and go back and try again at a different time and now maybe not go quite as far and see if you can get away with that. Sometimes it's disastrous today we had a fit today because we were supposed to write about what he did yesterday. He wrote a little something. It mostly had to do with the mix up between the buses that we had and where to get off and I didn't want that to be the center of his journal

entry for yesterday and so we tried to go through what other things happened yesterday maybe more positive things and...

MARY: It did not really work out

MATT: It didn't work out. He was very upset that he had to write, that he couldn't play on his computer, that...

MARY: He doesn't like to write because he doesn't feel he's good at writing. If he isn't – if he doesn't feel he's good at it then he doesn't want to do it. Now that may be typical of every child, but I think the emotional response is atypical that it gets to such a point that he shuts down completely. Because he just can't process that.

NOELLE: Process that things would be different from the expectation?

MATT: Yeah that...

MARY: He doesn't understand that practice makes perfect, he wants to jump right to perfect.

NOELLE: I can relate to that, yeah.

MARY: Yes, yes. That's what they're working on now in school that practice will get you to perfection. He learned to skate it takes anybody a long time to learn to ice skate but now he can ice skate fantastic. Or skiing we take lessons in skiing because if you don't you can't ski very well, you fall down, you get very cold...

NOELLE: And what about art? He takes music lessons doesn't he?

MARY: He takes music lessons. Of course Piano is much based in math, which is very easy for him. But he doesn't like music he doesn't like Spanish because it's just too... it was learning the Spanish language and he didn't like it at all because it was too simple. It didn't actually go anywhere. You didn't learn Spanish; you just learned a couple of words and you sang a song, which to a child should be fine but he wanted to learn Spanish. If you're not going to learn Spanish why waste my time? Singing a song about red and blue, that's not going to get you anywhere because nobody sings a song about red and blue in the real world.

NOELLE: So already thinking at that level.

MARY: Yes he's already reached metacognition. He's already reached that where with most people that would take you at least until college.

NOELLE: You have a particular interest in developing Harry's creative side a bit more is that right?

MATT: Yes I think it comes from having an art background and wanting to share that.

NOELLE: Your art background?

MATT: My art background. which is difficult because it's not a great match. I'm excited the Escher exhibit is coming up in Rochester and since Escher deals with... tessellations and it has more mathematical base and more optical things that perhaps would be a good way to get Harry interested in the art field in some way. I don't think he'll ever be an artist or a poet or someone who is highly creative but I think .. I would hope it would be part of his existence to be creative in whatever he does.

NOELLE: And what have you taken him to see in Cardiff?

MATT: Lets see, we took him to the castle. I thought eight-year-old boys would like to see a castle and I think that was pretty successful.

MARY: We took him to see the Roald Dahl exhibit which was a little bit close for him, a little bit claustrophobic. But he enjoyed it nonetheless. We took him to lots of shops. Which... he needs to understand that people like to shop. You don't just buy what you need online that there's an enjoyable part of shopping for different things. 1:44 We'd eat in small eateries to show him there's a connection between his food and the people who make and serve it that they're real people as opposed to McDonalds, which are automatons and can be easily interchanged so we tried that quite a bit. What else did we do? We'll go to a railway museum but then again that's not really creative that's engineering which he likes very much the engineering and mathematics aspects

MARY: On the flip side if you have to choose something for your child... starving artist? Successful engineer? Many people would say that being a successful engineer would be the most positive, good thing that you could possibly want. As opposed to a creative artist who was only successful after they were dead. So...

MATT: So the things we've avoided are art museums... I went to the Royal Pavilion to see the palace and I thought initially that Harry would like that but Mary didn't think it would.

MARY: We went to a chocolate shop, which Harry liked immensely seeing all the different types of chocolates.

NOELLE: Does Harry like chocolate?

MARY: Harry likes chocolate. And we got a very large piece of cake which we got to discuss with the lady who makes the cakes which was very enjoyable and we discussed what papa would like the most, what cake, and since we couldn't decide we bought the cake with all the different layers in it.

NOELLE: Wow.

MARY: Yes, and then we looked around and decided what else did we want? For the for the future not just right now but we discussed the future

NOELLE: What came up?

MARY: We just got some creams . we did not get the chocolate covered marshmallows or the chocolate covered popcorn we didn't think that would last. We got a very small box of candy

NOELLE: So you're talking, like, near future.

MARY: Not near future, the future when we get back.

NOELLE: Oh!

MARY: Cause there's plenty to eat now, but this is a small box that will not crumple. Because popcorn would just get all crushed. As would marshmallow... would get all crushed. These are in a sturdy box that will not get crushed.

NOELLE: So you'd done some clear planning.

MARY: We'd done some clear planning.

MATT: Chocolate engineering there

MARY: We got chocolate engineering going to make sure that it could actually get home and share with whomever. Because some of the other stuff was too fragile. Yes. So that was our very exciting [laughing] that was our very exciting time out.

NOELLE: Was that today or was that yesterday?

MARY: No that was Brighton, two days ago we were in Brighton. We went to quite a famous chocolate place.

NOELLE: You were talking about the connection bit, the human connection, can you speak a bit more about that? Do you find that very important for Harry to understand?

MARY: Yes. That there's a connection with the food you eat and the people who make it. That it doesn't just spit out of a vending machine. That there's people farming, there's people delivering it. People putting it in the store. There's people making it. It just doesn't get served to you at the dinner table.

NOELLE: Is that something that Harry intuitively or is that something he's still figuring out? In terms of connecting to other people.

MATT: I think he's starting to understand it but I think there's part of him that just sees the need to eat and then the product to eat. [he] doesn't see... he's not interested in the process there which amazingly he's very interested in the process. He... I've got a really good story about how when we went to the zoo... we used to go to the zoo, we used to have a membership to the zoo and Harry paid absolutely no attention to any of the animals. None. Did not like to go and see the animals but there was a diagram of different foods that the animals would eat.

MARY: Yes.

MATT: But they were part protein part, uhm... the herbivores the carnivores and who ate what. And it was illustrated by balls of colors in a conveyor belt system and he would just play with those balls in the conveyor belt system. And look at the different quantities of balls in different colors. And that is what he went to every time we went to the zoo and spent a half hour playing with but...

MARY: No animals.

MATT: But no animals.

NOELLE: Why not?

MATT: He's just attracted to the mechanics of it the mathematics of it not the actual animals not the...

MARY: Why would you go to see an animal at the zoo when you can watch them on T-V? And why is this animal in a zoo when he should be out living where he needs to live?

MATT: And how does this animal interact with me? Why is it important to my life? It wasn't important to his life.

MARY: No. We do not eat these animals. We do not play with these animals. We cannot touch these animals. These animals don't do anything. Who cares?

NOELLE: So is this pretty typical of Asperger's?

MARY: I have no idea.

MATT: Uh, yes I think it is. I think it's very much a focus on the practical side and not the enjoyment.

NOELLE: Interesting. So when the testing did get done and when you did find out, what was the next step for you?

MATT: To immediately get him some attention and some help. To try and.. I would say to overcome it. I would not hesitate to say that. I mean I think it adds to his personality a unique dimension and I don't want to erase that completely, but I want to make him so he has a happier life. So I think we need to not eliminate those things but to...

MARY: Be able to fake it in society enough to get by.

NOELLE: And what would be some of the challenges he would face if he weren't able to kind of adapt?

MARY: He wouldn't be able to get ahead in the work force. He would have a very difficult time in college. He couldn't interact -- just asking things on the bus you have to be extra nice. You ask very nicely and politely, someone is more likely to give you a proper answer. To go out of their way to give you a better answer than: no. Is this where you get the bus? No. Sir, is this where you need to go get the bus? "Oh no, no, no. You need to go over there."

NOELLE: So these social skills...

MARY: And he just needs to fake the social skills. That's fine. More people should try to fake social skills.

NOELLE: So it's a matter of... um... when you say fake it, so when it comes to parenting, are you giving him a script?

MARY: Yes. We are giving him a script. We're telling him: this is what you need to do and that's that.

NOELLE: And do you tell him the result that...

MARY: Yes. We will tell him point blank the result. If he does it, and if he does not do it. And usually we are correct.

NOELLE: [laughs] Okay. So do you , with other things as well, do you give it in a clear black and white for him? Or do you allow there to be grey?

MATT: It depends, it depends how much energy we have. If we don't have enough energy we'll give him a clear black and white. If we have the energy to make it a learning point then we'll go for the grey.

NOELLE: And if you go for the grey, does it take a while?

MATT: Yes, it's quite a struggle.

MARY: Not just minutes. Perhaps days, perhaps weeks, we have to stretch it out over and over and over again but eventually he will understand that this is what you do. You smile.

[Matt and Noelle laugh]

NOELLE: Good demonstration!

MARY: You are nice. You speak, you say please, not just "I want". You look interested whether you're interested or not.

NOELLE: Do you have to give an example of an interested face?

MARY: Yes!

MATT: Yes we do.

MARY: Yes we do.

NOELLE: And on this trip has anything like that come up have you had the learning processes?

MARY: Yes when we get on the bus, exactly, we ask politely about the bus: where it's going, where do we get off, this is where we want to be, and the bus driver in turn will tell us the correct answer.

NOELLE: And do you have Harry talk for you?

MARY: We do try, I try to have Harry ask questions especially when it pertains particularly to him. If he wants a plug to plug in his phone I will have him ask. And now he knows if he asks more politely he is more likely to get a plug which is what he wants.

NOELLE: So he gets that trial and error.

MARY: Yes, and he knows that if he is not polite he will not get it. Very slowly, he's getting it.

NOELLE: Are there other things than the bus and the plug that have come up?

MARY: Here on this trip? I don't think so?

NOELLE: Are there things back home that would happen that are happening here? Or are you seeing a change? I guess that's vague, but perhaps there are things back home that are every day and this is the routine and I know that this is going to come up because it's this time? Is the routine changed?

MATT: I think we try to keep the routine as much as possible. But a learning experience is also to break that routine. So that's where the challenge comes here. Yesterday he wanted to go back to the hotel after 2 hours and we said no this is what we're here to do we're here to walk around and see things and he doesn't quite understand [that]. We'd seen the castle, the adventure was done and now it's time to retreat back to bed and video games and television and..

NOELLE: Like a safe space.

MATT: A safe space, yeah.

MARY: And we had no real plans. He did not like that.

NOELLE: So what happened?

MATT: We had a couple meltdowns.

MARY: Yes but then we had a break, we walked around a bit more, I took him to the hotel. He was good being back here and relaxing for half an hour. And then we had a plan we were going to meet you for dinner so once he knew the plan we were back on track. Vague does not work.

NOELLE: Okay. And when you say meltdown could you break that down?

MATT: A complete shutdown. Sometimes there's tears and pouting but most times it's kind of a shut down quiet: likes to put his hood up, likes to keep his eyes and face down. If he can retreat to his phone he will just to try and find his center again or safe spot.

NOELLE: So it sounds very inward. When I imagine a meltdown I imagine like a huge explosion.

MATT: Sometimes it can be because we're trying our best to get him out of that. And sometimes we get angry because we're doing our best and nothing is working. And we keep trying a different tact and that doesn't work. And we'll lose our cool. And then, he'll get more upset because he doesn't like us to lose our cool.

NOELLE: And with Cardiff, did you find anything of particular interest?

MARY: I always like to take him on alternate forms of transportation. To show him that it's not all cars. Sometimes you have to be social and sit with other people.

You have to talk to other people in line to find out information. Sometimes you just talk to other people because it's a nice thing to do. In the US it's just cars cars cars, you never have to interact with anybody. But in Europe it's more social. We talked to people on the train, Harry didn't understand why we [were] we don't know those people why are you talking to those people? So, we said it's just a nice thing to do and they told us about different spots they'd go and why we didn't get charged for the train because it was 20 minutes late and now if a train is late they have to give us a refund. A piece of information we did not know so we pointed that out. See if you wouldn't have talked to them you wouldn't have found out that you could get a refund and look at all the money we saved. So those are practical things and it kind of helps him to see why it's important to be social. And then maybe other social things will kick in. You've got to start somewhere.

MATT: He really enjoyed the castle. He liked the idea of engineering a defensive spot. How it was engineered to be defensive and the small slits that allowed you to move around with a bow and arrow but to keep yourself protected, the defensive walls how those operated. He really liked the catapult because it's a great example of engineering, levers, so he liked that. He liked the audio guide that went with it because he liked pressing the buttons at the different spots on demand.

MARY: not having to wait for an interpreter, he could decide what information he wanted and when he wanted it. He didn't have to wait on a person.

MATT: It was more anonymous that way. And he's more comfortable with that than with it being a person that could at any point do something unexpected. This way it's all in his control.

NOELLE: And predictable.

MARY and MATT: Yes.

NOELLE: So I imagine with the Roald Dahl exhibit then that there was a lot out of his hands.

MATT: Yes I think he was a little concerned because we were working with a tour guide and he would have preferred if it were done with buttons and tape recordings and the voice over that was part of it and he was concerned in the forest that something was going to jump out at him. He doesn't like the unexpected like that he doesn't like surprises in general. Some pleasant surprised, I'm thinking about Christmas when he got a bed from Santa and I've never seen him that happy when he'd gotten his bunk bed. He knew there was going to be a surprise, a nice surprise.

MARY: Anything could have jumped out t you at the forest at Roald Dahl.

MATT: But I think... I don't know if he would appreciate a nice surprise if he didn't know to expect a surprise coming. Which isn't really a surprise. I think he would be

completely overwhelmed by say a surprise birthday party. It would be unpleasant for him because it would take him so long to adjust to there being a birthday party where there wasn't one before.. that the birthday party would have ended by the time he got to that point.

MATT: He really enjoys the trains and buses because they run on time or relatively so they tell you when they're going to be there, he actually enjoys that. You can see a smile on his face.

MARY: He did not enjoy that they had closed the street and moved out bus stop.

MATT: Yes he was very upset about that. He couldn't understand why the sign that said the bus would be there in 3 minutes was still going even though the street was closed and there was not going to be a bus. It was unforgiving that they would have not turned off the sign.

NOELLE: So then back home, do you not have buses like this?

MATT: We do by the quality and quantity of public transportation is far less. Though it's something we typically don't use. We'll do it on occasion for the novelty of it. And get him used to ..

NOELLE: Why is it important to take Harry traveling?

MATT: I think it's important to anyone to go traveling just to see that there's a different way of life somewhere else. And also to see the variety of the world. That there's more to life than what's in your own backyard. That's a wonderful place and there's a lot of discovery to be found in your own backyard, but there's so much else out there. We have always traveled, Mary and I. We connected by traveling and when we decided to have a child, one of the reasons we decided to have a child was that we could share all of the wonderful things that we found out here, so we really hope that he appreciated them now it's frustration when he doesn't because we've tried... that was part of the plan from the beginning and when you have to abandon your plan, sometimes that's difficult. But we haven't abandoned the plan I think we've just modified it so that we do different things. Last time we were in London we went to the Tower Bridge and saw how the mechanics of it worked with the steam engines, and the hydraulics and that's what's fascinating to him. When we went to Paris he was enthralled with the Eiffel Tower because of its structural engineering, the elevator system. He was seven. That's what he's interested in. Not the Mona Lisa, not how beautiful the gardens are. He's interested in how the fountains work.

MARY: Which is fine.

MATT: Which is fine. That's him. I can understand him not appreciating...

MARY: -- The water lilies. I wish he did but he doesn't. That's OKAY. Lots of people don't appreciate Monet's water lilies.

MARY: Its okay because I don't really have the patience for giant museums I get very lost so Harry and I will go do something else. That's just what we'll do. We'll go explore something else and he finds that just great fun because we have a plan and we're only going to do it for an hour. There's always a time limit. We always tell him: we're only going to go for an hour. And he's okay with that as long as he knows it's not forever, yes. And he knows I will keep to that time limit because we will be meeting his father. I tend not to deviate from that.

NOELLE: and this is something you've learned to do by working with him?

MARY: Just by trial and error. Yesterday was fine because we were going to meet papa in two hours. It was a known quantity. It's the unknown that's frightening. It's frightening to most people.

MATT: I think we do things now that we wouldn't have done without him which is fun for us. I mean to go to... I don't know that we would have gone to see the inner workings of the Tower Bridge or would have paid so much attention to the way the Eiffel tower is built and hydraulics and the scientific part of it so we're really, we're on the benefit of it too. I mean, I'm learning to look at the world in a different way through his eyes and that's the positive thing because at fifty years old it's good to look at [the world] through somebody else's eyes we've looked at it long enough.