

HUMAN POTENTIAL AT WORK

Host - Debra Ruh



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Donvan

Guest: John Donvan

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Debra: Hello. Welcome to Human Potential at Work, with Debra Ruh. I do have my producer, Doug Foresta, joining us again today. I thought it would be interesting if Doug and I co-interviewed our guest, because we're pretty stoked about our guest.

So our guest is John Donvan, and I want to turn it over to John for a minute, just so that you can introduce yourself, John. I want you to talk about your work and the book.

John: In one sentence, I wrote a book called "In a Different Key: The Story of Autism" which attempts to capture the long and tumultuous journey of the diagnosis of autism and how it has impacted those who have been given the diagnosis, and their families, over many, many decades, as all of those people have fought for a place in the world for people who are on the spectrum.

Debra: And John, tell us what you do for a living, besides being a best-selling author.

John: The best-selling author part is pretty new; it just happened this year.

Debra: Yay!

John: That's after working on the book for seven years with my colleague, Zucker. Karen and I had, before that, and I still do to some extent, long careers as journalists with A B C News, based out of the New York bureau. Karen was always out of New York. In my career, I spent years living overseas. I lived and reported from London, from Jerusalem, from Moscow, from Amman Jordan, and covered as well Africa and eastern Europe and a lot of the Middle East, and got to see a really big chunk of the world during those years. Not all of it, but a lot of it was sort of big-scale stories, wars and famine and disasters and royal weddings and the fall of the Berlin Wall and things like that.

HUMAN POTENTIAL AT WORK

Host - Debra Ruh

It was only in the later part of my career that I started reported on disability and autism in particular. That started in the very late 90s. As a result of two things, I became interested. One is that my wife, whom I married in the 90s, is from Israel and she is the sister of a man with autism, whose autism is very, very impairing in his life. He's not independent in any way. He's middle aged now, and he's -- I would say he's a happy and content man, but he needs constant support, really 24 hours. He can't speak, but he can paint like nobody. He's interesting company. But when I met him, he wasn't like anyone I had met before, because people who are as affected by autism as he is, have as a rule been kept hidden from society.

And then coincidentally, Karen Zucker, my co-author, who was a producer at A B C, I was on TV, she was behind the camera, and in the 90s when I came back from my overseas work, she was one of the producers in New York and we started doing a lot of stories together about all kinds of things. Some of them happened to be actually civil rights stories, but we also did politics and some science stories, things like that.

And then her son, in the late 90s, at the age of two, was diagnosed with autism. It changed her life dramatically. She, in a sense, sacrificed the career path she was on because she went into a job share, half-time working situation, and that never changed because she had to spend so much time on behalf of and for her son's shot in the world.

She said to me, "Would you give me a hand in telling stories about autism?" This started in 1999. She said, "Because I know you know a little bit about it through your wife." So we started doing stories about autism for A B C News, and the interesting thing is, back then when we went to A B C and said we'd like to do stories about autism, they really didn't know what we were talking about. I'm only talking about 16, 17 years ago, but consciousness has changed, awareness has changed so much, that if you wind back the clock, if you go back 16, 17 years, there was very little awareness and people didn't know what we were talking about.

But Nightline was the show they gave us our chance to start telling the stories, and we began doing that, putting on stories that we're very proud of to this day, about the reality of autism. There was a little bit at the time, maybe every now and then about a miracle cure kind of story, or there would be stories about somebody with Savant skills, but those didn't have very much to do with the reality of life as an autistic person, or the lives of the families that needed to support them. So we wanted to tell those stories.

And then the book came about because around 2005 or so, we wanted to do something that would feel more enduring, because TV pieces, they come and go, especially in those days when there wasn't any such thing as links in the internet. Once a TV piece was on the air, it was gone forever. You never got to see it

HUMAN POTENTIAL AT WORK

Host - Debra Ruh

again. So we decided to do a book. Something that would sit on a shelf and would really get into peoples' heads, because they would be living with it for a long time as they read it.

We set out to write a book about history of autism, partly because we found out that there was this sort of turbulent story, and also because we kind of came to the conclusion that the past can serve as an instructor for the future. It can teach us about the future and it can inspire us about the future, and there are lessons to be learned from the history of autism, which we think applied today and for the future, as the continuing challenges of people who are on the spectrum, still need to be faced. There's some good news from the past, and we think that that will inspire people for the future.

Doug: John, this is Doug. Can you say a little bit more about what you mean by the good news about the history of autism? From the little bit that I can understand, it sounds like it was fairly terrible.

John: Well, Doug, it was terrible. Karen and I usually boil things down when we talk about this, to three or four different things that stun people. One of them was that there was absolutely no real understanding of what autism was about. Autism was judged to be the result of mothers not loving their children enough. The theory that was not only dominant, it had an entire lock on all discourse about autism in the psychiatric profession, was that mothers failed to love their children, they acted coldly towards their infants' first days of life, and that the infants, recognizing that they had been rejected, therefore as a defense mechanism, constructed this world to which they withdrew, and that they were trying to protect themselves by therefore "becoming autistic."

This idea persisted for decades. You can figure out what the consequences are. Number one, no real help was being given to the children, who of course grew up to become adults. The other part, of course, was the enormous guilt that was piled on mothers. Stories we tell in the book, because Karen managed to find some women who had lived through this period, who had to live with the label refrigerator mother, because that's what they were called. That they were so cold towards their children. So that was bad news.

Other bad news. People who were diagnosed with autism were almost always institutionalized, usually for life, and in an era when institutions meant these horrible, huge warehouses of dozens of people crammed into a room, with very little oversight, no stimulation. Sometimes not even clothes to wear. There was no such thing as a right to an education for people who were disabled. Nowadays, families are quite well-versed in the idea of the I E P, the Individualized Education Program, their rights under that program. They might not be perfect, they may find the process frustrating, but there was no process. The children had no right to education. In the case of autism, we tell many stories of families who

HUMAN POTENTIAL AT WORK

Host - Debra Ruh

went to their public schools saying, we need help, we need education, and they were told we don't want your kid.

What's the good news? Good news is all of those barriers fell because of activism. And that's one of the lessons of our book. Activism works. The story can get better. And as a result of activism and organization, dedication almost entirely by parents during the first 40 to 50 years of this story, parents were on their own. People with autism were not yet self-advocates, because for the most part people who had the diagnosis were more impaired than many people who get the diagnosis today, as the definition has changed. So it was done by parents. Parents who started out as amateurs, who didn't know anything about the legal process, who didn't know anything about science. And what they did is, some of them literally went to school. They went to court. They fought back. They staged protests. They lobbied. They begged. They went to the media. They figured out how to get their kids' stories into the press. Very, very, very slowly, they began to fell these barriers.

So it was a parent who wrote a book, back in the late 1960s, mid 1960s, that began to chip away at the refrigerator mother theory. A parent did that. It was parents. Primarily, by the way, parents from the intellectual disability community, not the autism community, who led the charge to close down institutions and insist upon a right to education, that ultimately was enshrined in law.

It was parents who went out to universities and other research centers and talked to young researchers, geneticists, et cetera, talked them into switching their career focus to study autism. They also came with money. They went out and raised funds and they said to these young researchers, we know you think there's no future in a career that's about autism research; we'll give you one. We'll fund you. And they did that on a large scale.

So the good news is that the world can be changed through activism, and I think the good news also is that the larger community, the communities that surrounded the autism world, which we often use the phrase in the book "the rest of us," everybody else who didn't really know very much, once that larger community got the message about the reality of being autistic and of the reality of the support that was needed, the heart is there. The heart is there, and the larger community wanted to help. That's why the laws got passed. That's why the courts made the decisions they did. That's why the institutions were closed.

There was a scene that took place in a courtroom in Philadelphia in 1972, when a lawyer named Jim Gilhool, was suing the state of Pennsylvania over its refusal to provide education for people with intellectual disability. He got up and made his presentation. The state had a whole lineup of experts to argue against him, to say basically that the children were uneducable and therefore should have no right to

HUMAN POTENTIAL AT WORK

Host - Debra Ruh

education. That afternoon, the attorney for the state of Pennsylvania, when it was his turn to present his case after Jim Gilhool spent the whole morning making his case for education, he stood up, having heard what his opponent said, and said, "Your Honor, I surrender." That was the turning point in that case. People will hear the message. The goodwill is there, as long as the information can get out.

So that's where I would say the good news is from the past.

Debra: And I think we need to always remember history, so we can learn from it and try not to make the same mistakes, because there's been some bad mistakes made with autism. I read the book and I just think it's brilliant, and at times chilling. I will also tell you that as a mother of a daughter with Down Syndrome, I remember when they told us Sara had Down Syndrome, I had somebody ask me -- well, my mother ask me if I took drugs while I was pregnant. By the way, we don't know what causes Down Syndrome. As a society we don't know, but it's not drugs.

John: Right.

Debra: Now, drugs and alcohol will damage a fetus, but it doesn't case a fetus to have an extra chromosome. And to make me feel guilty when I already was just stunned and devastated, by my mother -- anyway, she was processing it as well, but I had never heard that, refrigerator mothers. As a mother, that makes me very sad.

So I'm really glad that you and Karen took the time, because it took you many years to write this book because it's a powerful, powerful book.

John: Yeah, we said we would deliver the book in two years, and it took us about five and a half.

Debra: And it's an amazing story. So the book starts out as a story of the parents, but then as the book evolves, it starts talking about individuals with autism. So let's talk about that for a moment.

John: Yeah, that's a pivot that took place, actually, in the history, and so the book reflects that. We're talking about 70, 75, 80-year period, from the time autism came into focus as a diagnosis. For most of that time, autism was defined -- and the definition has changed a lot. That's another theme of our particular book, is that we're not always talking about the same thing when we use the word autism, even if we think we are, and that's a source of a lot of the, unfortunately, endemic strife that has always gone along with the autism conversation. There's a lot of arguments in autism, which we think is because of this definition problem.

But very broadly speaking, the definition got bigger and bigger, to include more and more people, particularly in the last 20 years. And that change in definition

HUMAN POTENTIAL AT WORK

Host - Debra Ruh

brought into the labeling arena -- by labeling, I mean being given the diagnosis of autism, and that's a word I instantly just now regret using, because labeling has such negative connotations to it, so I just want to be clear that what I mean is more people were able to get the diagnosis of autism in the last 20 years than ever before, because the definition got bigger to include people who were far more capable of independence in life. People with very, very great verbal facility and very established normal to high levels of intelligence, to the point of super high levels of intelligence, where there are probably college professors and physicists, who would now meet the diagnosis of autism, based on deficits in their social set of skills.

And so that's a lot more people, but that lot more people, that additional group, they could speak for themselves. They could speak for themselves in ways that were easily recognizable by the rest of us, to everybody else. About 20 years ago, in speaking for themselves, they began to do so and they began to activate -- they became the activists as well. So up to that point it was the parents, but about 20 years ago it became this pivot to people who are on the spectrum themselves, according to current definitions, and who demanded respect, who demanded acceptance, while also demanding support. So they were not saying, strictly speaking, we're not disabled. They were saying we have some disabilities but we also have a lot of abilities. We want those recognized and we want them respected and we want those celebrated.

So I would say that's the newest and most important pivot in the autism story, and it's only happened in the last 15 to 20 years.

Doug: So John, what in your opinion still needs to change? What's the next evolution, when it comes to autism?

John: We have a pretty clear answer to that, Karen and I. We need to recognize that autism is lifelong. By that, we mean that for most of autism's history, and even to some powerful degree today, it's a condition that is seen to be related to childhood. Even the first official diagnosis of autism back in the 1940s, it wasn't called autism; it was called infantile autism, meaning childhood autism. All of the studies that took place -- nearly. I shouldn't be so absolute, but the vast, vast majority of the studies into autism that took place over the succeeding 50 years, were focused on children. The research was about them, the writing was about them, and more importantly, the advocacy was about children. The ads, the billboards, the TV commercials focused on children with autism.

The responses, that society now warmly embraces to support people with autism, are focused on kids. You'll see that the local movie theater is going to have special showings of kids movies for kids on the spectrum, where they turn down the sound and maybe turn up the lights so as to minimize some of the sensory jolts that some people with autism experience. There will be a barber shop in town,

HUMAN POTENTIAL AT WORK

Host - Debra Ruh

and I've done a story myself, there's a guy outside Baltimore who early on -- a lot of kids with autism hate to be touched and getting a haircut is kind of a very, very challenging experience for everybody involved. Well, there's this guy outside Baltimore who for years has made it clear that if you have a kid with autism, bring him in here, I can work with him, I'll give him a haircut. Dentists, the same thing. All of these responses for kids with autism.

And so Karen and I say, you know, we've come such a long way in really giving that embrace to kids with autism, but you know who that leaves out? It leaves out adults with autism. And we really haven't come up with a solution for the broad set of challenges for adults with autism, and there are a lot of them. The standard figure is that every year or something like 50,000 children with autism become adults with autism. They turn 21, essentially. Because of the definition of autism, that represents a very, very wide, wide range of people, in terms of their ability to be independent, but a lot of them can't be independent at all, and all of the rest are going to need some support or something else, if they're going to have fulfilling, real adulthood.

What do I mean by real adulthood? I mean the kind of adulthood anybody wants, where you have a job, you have a job that you want, that you choose, if possible. You have a place to live on your own, if possible. You have friends, you get to choose where you go every day, what you're going to eat every day. All of that's the opposite of being put in an institution, which is where the adults used to be. They'd be put in an institution, they'd stay in the same room all day, maybe a bus outing with a group of people, and the institutional menu would tell you what you were going to eat that day, when you were going to eat and what clothes you were going to wear. So we're talking about real adulthood, which is choices and independence.

Well, we're not very good at that. That hasn't been worked out. Because we don't have institutions anymore, where are all of these adults? They're at home with parents who are getting old and who are going to die. We talked with a lot of parents, and Karen feels it herself as the mother of a now adult son with autism. Her young guy is 22 years old. A year ago, he got too old for the support that comes with the school systems. That runs out at 21. And the school systems came such a long, long way in answering the needs of kids, but not adults. It's a very, very huge challenge that hasn't been answered.

Karen says it. Her son's really turned into a handsome guy, but she says, he's not cute like a kid, and she says I can see people being scared of him on a day when he's walking down the street and maybe he didn't change his clothes in two or three days because it's not a high priority for him, and maybe he didn't shave and maybe he's talking to himself. Maybe that's scary to people.

HUMAN POTENTIAL AT WORK

Host - Debra Ruh

Debra: Yeah, and you know what's so interesting is that many adults with autism are actually in the workforce, and we're seeing some very interesting programs. I know SAP, Freddie Mac --

John: Microsoft.

Debra: Yeah, Microsoft is one of the latest ones. Vodafone. They actually have really great programs, where they're employing adults with autism. Not because, oh it's the right thing to do, or pity, but because these are very qualified candidates for work and they actually are adding great value to the workforce. But I think part of the problem with autism is the wide spectrum, right? Because some of my daughter's friends that have Down Syndrome and autism, that are on the lower end of the spectrum, it's a really wide spectrum. Go ahead, John.

John: Yeah, well, I'll give a two-part answer to that. The first part is, yes, there are people who have the autism diagnosis who can make enormous contributions, if they get into the right setting, one that plays to their strengths. And so Steve Silverman, who wrote the book "NeuroTribes," wrote a really interesting piece back in 2001, about the high prevalence of autism diagnosis out in Silicon Valley in the high-tech industry, and program coding, computer coding, where being autistic can actually be an advantage in terms of great memory, ability to systematically organize ideas and data, ability to look at small details, be tolerant without getting bored. That's a real thing. Those are real gifts, if put in the right situation. That's not a particularly great set of gifts in all situations, but there, it is.

Karen and I did a story back in 2007 or so. We went over to Copenhagen, where there was a man name Thorkil Sonne, wanted to prove that individuals on the spectrum -- the way you put it, Debra, it's not like a charity thing, exactly what you're saying. He didn't want it to be, oh it's nice to help people on the spectrum because they don't have jobs. Well, yes, it is, but he wanted to prove something else. That they have economic contributions to make.

And so he set up a company, a for-profit company, where he hired only people on the spectrum, to test software. So if I wrote some kind of computer program that has 60 different menus and every menu has 14 items on it, that's a lot of different combinations. And so this is a company that goes through every single combination and makes sure that it's working, and if it's not, they note it down.

He got a special dispensation from the Danish government, to allow him to hire people only on the spectrum, because actually that's discriminatory. But he got that dispensation, and he started hiring people who could do this work. And we went over there and interviewed people who had not -- again, they were people with quite high intelligence and great verbal skills, but terrible challenges when it

HUMAN POTENTIAL AT WORK

Host - Debra Ruh

came to the social arena, who hadn't worked in years and years and years. They were basically getting welfare.

We met a guy in his 40s who hadn't worked in years. I said, "Well, what have you been doing?" He said, "I've been sitting home, watching television." I said, "How was it?" and he said, "I would so much rather be here." He would rather be there because he felt important, he was making a contribution, he met a woman who was a colleague, who also was on the spectrum, same story with her. They met each other there. Really interesting innovation that Thorkil had was he knew, because he understood autism, that people on the spectrum are really, really likely to be bad at job interviews, because you have to make eye contact, which is very hard for a lot of people with autism, and you're going to have to answer questions that are coming in and out of nowhere, you're going to have to read body language. He knew all of that was a challenge.

So what he did, he developed, instead of a job interview program, he developed an exercise based -- Lego robots. Instead of an interview room, he has a large room with a gigantic sandbox, and he would give an interviewee an assignment to build and program a robot to do something in the sandbox. And after that was done, he would pair two people together to see how they worked as a team and how they solved problems. And that became his substitute for I'm going to hire this guy or not that guy; I'm going to hire this woman or not that woman, rather than having to sit there and talk a good game and sell yourself. These guys got to sell themselves through their capabilities as programmers and as problem solvers and as systematizers. It was really a brilliant stroke.

So Karen and I, then we went out to one of the -- we've been doing a lot of talks around the country since the book came out in January. We went out to Microsoft and gave a talk there, and Thorkil Sonne had just been there and helped set up Microsoft's program, hiring people on the spectrum.

So that's all progress. That's all a step. The thing is though, I mean you've already said this, it's a big spectrum. My brother-in-law cannot work in one of those places.

Debra: So Jon, I know you have one more story that you want to share before we close up, so the floor is yours.

John: It's the story of Donald Triplett. Donald Triplett was the first child diagnosed with autism, according to the medical literature, in the first article published about autism back in 1943. He was listed as case number one. There were 11 children described; he was case number 1. Cases 2 through 11 were, I think now, 2 girls and 8 boys. He was case one. Well, he's the centerpiece of our book. Karen found him. He lives in a little town in Mississippi. He's 83 years old, and we got

HUMAN POTENTIAL AT WORK

Host - Debra Ruh

to learn his story. And it's so encouraging. Again, how the past brings some light to the future.

This was a kid who was very, very severely impaired, who couldn't really use language in ways that people would recognize, who seem to have no interest in human beings at all, and whose parents got him to a child psychiatrist named Lee O'Connor, who wrote this article, introducing the concept of autism to the wide world.

Well, Donald's life, when we found him, when Karen found him, by the way he's 83 years old in September of 2016, he turns 83 years old. He lives in a little town, the town he's always lived in. It's a town called Forest, Mississippi, population about 3,000, and he has had such a wonderful life. He has grown to his full potential in an amazing way, helped by the fact, no doubt about it, that his parents had money, they were able to set up a trust fund for him, and they had clout. They were able to make it clear to the community that they wanted their son respected. And they had clout because his dad's father was the mayor of the town and his dad himself had gone to Yale Law School, and his mother was an educated woman whose grandfather owned the bank in town. So they had clout, and that was important, no doubt about it. Not everybody is going to have that.

But the end result is that when we went down there, we found a town that absolutely embraced Donald. People love him. And so that told us a lot. And when we finally found the full story, we found out that Donald, the guy whose symptoms described this socially challenged thing called autism, who had he turned into? He turned into a guy who had friends in town, whose language was very easy to understand. He's not chatty, he's not somebody who could converse, but he communicates perfectly with language. He picked up some hobbies in life. He plays golf every day. He drives himself around in his own car. He takes trips around the world all the time. Even as we speak, right now he's in Panama, I happen to know. He's been to a lot of countries around the world. He goes by himself.

Well, look how well things have turned out for him. What happened was his mother put him in an institution when he was three, and then she pulled him out. She changed her mind somehow and she started fighting for him and gave him a place in this world and made sure, using her clout, that he got into the public school in his town.

The other thing, where it comes to work, they gave him jobs in his parent's bank. Again, I'm copping to the fact that not everybody's parents are going to have a bank, but look at what happens when you do have that entre, that access. They gave him a job as a teller, because he was always very good with numbers and arithmetic. But he was so good with numbers that he fell into the habit, when people started walking into the bank, that he would greet them by their account

HUMAN POTENTIAL AT WORK

Host - Debra Ruh

numbers and he would shout out the balances in their accounts, because he had all this stuff, he had it all committed to memory.

So here's the lesson. If Donald's parents hadn't owned the bank, he would have been fired. But because he had somebody on his side in an important position, he got a second chance and he got a third chance and he got a fourth chance. He got the chance to make mistakes, because they understood who he was and what he was about. He in time, learned not to do that. He ended up getting relocated in the bank to a back office where he did work that suited his talents better and didn't do social skills as much.

Now, all that happened because there was somebody on his side, his mother and father, who had the power in the bank. Two lessons from that for us. One is, okay, you're not going to own a bank but if we can get society into that mindset of let's have the backs of these guys who are different and need help. Let them make mistakes. Let's come more than halfway, maybe move them to a different job, maybe a little extra training, don't freak out because they're yelling out the balance in peoples' accounts. That just shows how far somebody can come when given the chance to make a few mistakes.

And the second thing is, as I mentioned, Donald was pulled out of that institution back in 1939, when he was three years old -- 1938, when he was three years old, and I just told you how he turned out. What a wonderful life he's had, so that he's on vacation even now. Of the other children described in that 1943 article, all but one stayed in an institution but the rest of his or her life, and they wilted. We know that. We know that they just wilted.

The reason I want to tell that story is it's the story of not only recognizing the human potential that was always there, and proven in Donald's case because he got out of the institution and got the support and love and embrace of a community, but it emphasizes the importance of the embrace of the community to helping -- I was going to say an individual with autism to reach his full potential. To help anybody reach their full potential. Having the embrace of the community is critical. So that's why Donald's story, we think, is so important to share now.

Debra: Yeah. I think it's a beautiful story, and I think we're learning so much still about autism. I really believe, and I know that all of us on the podcast today believe that people with autism, they're not broken. They just are using different parts of their brain, and there's major value to society to include them, meaningfully include them. And you hope -- because along my career, I've made lots of mistakes. I remember as a programmer, I made a mistake one time. I wrote or instead of and in the programming language, and accidentally cut 25,000 checks in a bank. Somebody said, "Wow, you really screwed up. If you do that again, you're going to get fired." But they gave me another chance. I didn't make the mistake again. So we all hope that somebody's got our backs, right?

HUMAN POTENTIAL AT WORK

Host - Debra Ruh

John: Right.

Debra: So before we close, tell us again about the book and how can people get the book and find out about the book, and if they want to bring you and Karen in to speak, tell them how they can get ahold of you.

John: Yeah, Karen and I are going all over the country now, and it's been very gratifying. So people can find us through our website. The name of the book is the name of the website - In a Different Key, and the whole idea of that is that we all sing in life. Some of sing in a different key than others, but we're all singing a song, so we should hear it. InaDifferentKey.com will lead you to inviting us to speak.

The book is doing so gratifyingly well, and it's available of course in the big places, Barnes and Noble and Amazon. We love independent bookstores, because they're some of the people who are really bringing us in around the country. So if you have a local bookstore, they need the support. There's an audio version, and the paperback is coming out in January.

One other thing I want to say about the book, we decided to be really serious about the history, so there's a lot of scholarly citations in the back of the book. So the book looks really big and thick and scary. It looks like, "Oh my God, that's a big book." We have 46 little stories in it that move forward through time, and the chapters are about 12 pages long. So don't be scared if you look at the book and you see it's big. We think it's really a pretty easy read, and we hope that it moves forward.

The other thing we hope for the book, we know already that people who are inside the autism world are liking the book and reading it. We really want people outside the autism world to pick up this book and read it, because it's our belief strongly that the experience of people who are on the spectrum is so shaped by the responses of everybody who's not on the spectrum. The outside community has a lot to do with this story. And so we want them to know that they have a place in the story as well, and that they have a place in this book.

Debra: Yeah, well said, well said, and I think that everything that we talked about today just goes on to prove that the only disability is not being able to see human potential. So thank you so much, Doug, and, John, for joining me today.

John: Oh, it's been such a pleasure. Thanks, Doug, and, Debra, so much.

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