

Stories from the brainreels transcript

January 1, 2015

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Introduction

CHERYL: Welcome to Stories from the brainreels. I'm your host, Cheryl Green, from [StoryMinders](#) up in sunny Portland, Oregon. This is a monthly podcast about brain injury and disability with a focus on art, culture, and disability pride. Contact me at info@storyminders.com with questions or topics and guests you want to hear on an upcoming show.

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CHERYL: [Autism Empowerment](#) is a nonprofit organization devoted to enriching and empowering the lives of children, teens, adults and families within the Autism and Asperger communities. You founded this organization, Autism Empowerment, in 2011. The vision you work toward is an inclusive society that accepts and respects all youth and adults on the Autism spectrum and empowers each person to reach his or her highest potential. You offer innovative and inspiring programs, training and services, and opportunities for leadership and volunteerism for those within and supporting the Autism and Asperger community. You serve all ages and abilities, and each of your programs and services promote Four Foundational Pillars of Positivity: Accept – Enrich – Inspire – Empower. There is a ton, a veritable metric ton, of great stuff in there. Before we pull all of that apart, I would love to have you two each tell us a little bit about yourselves. I'm here with John and Karen Krejcha, who're giving me thumbs up for pronouncing their name correctly.

KAREN: [giggles]

CHERYL: And you two are the co-founders of Autism Empowerment.

KAREN: OK.

CHERYL and KAREN: [giggle]

KAREN: Right now, we're pointing at each other because no one is brave enough to go first, apparently. But that will be me. John has a habit of volunteering me for those things anyway. He thinks it builds character. But I've told him it doesn't.

CHERYL: It makes you very brave and special.

KAREN: It does. Oh very much so!

CHERYL: Very brave and special!

KAREN: I think we should throw a parade. [laughs]

JOHN: Or a monument.

CHERYL: We're gonna throw a parade that leads to a monument-building. And the whole thing will be recorded for an after-school special. And it will be so enlightening to everyone. So on that note of extreme sarcasm.

KAREN: So my name is Karen Krejcha. I am the Executive Director and Co-Founder of Autism Empowerment. We co-founded in Vancouver, Washington in June of 2011. And I have been volunteering with Autism Empowerment since inception.

JOHN: I'm John Krejcha. I'm the Programs Director. I, too, am volunteering full-time. We have two sons on the Autism spectrum, currently 8 and 15. Our youngest has Autism. And our oldest has Asperger's.

KAREN: They're both on the Autism spectrum. But that was what their original diagnosis was. And they were both diagnosed back in 2008. So at the time, our youngest was a little bit before 2. And our oldest was 8. And our youngest was actually diagnosed first.

JOHN: And then 2009, we decided trying to again immerse ourselves in information. We actually drove back to a National Autism Society conference in St. Charles, Illinois. We spent a good, what, four or five days at the conference. As we were leaving, Karen was like, "Wow, these were just like my peeps." [chuckles]

KAREN: Well actually, it was before that. It was even as early as just walking into the conference and feeling, I don't know, a different atmosphere. That oh wow, I don't feel super anxious. And I don't have to immediately go into this script-mask mode to try to make sure I'm appropriate. And I can just be myself. And there's other people here that seem to get that. It felt comfortable. And I wasn't used to being able to go into big things like that and feel comfortable. And then I had, we had an opportunity. There was a session that was just for adults on the spectrum. It was just, it was empowering just to be able to see and hear other adults on the spectrum. And that was the first time we got to hear Dr. Stephen Shore speak and to know oh you know, and there's actually women. Wow, there's women on the spectrum!

CHERYL: [chuckles]

KAREN: We exist. Oh my goodness.

JOHN: It's not all males. It's not all kids.

KAREN: Wow, it's not all males. There's all sorts of information out there because a lot of women on the spectrum are very prolific and very generous in wanting to share. And that's a really good and awesome thing. But before that, I just really hadn't picked up on all of that. I think that for us, part of the reason we'd gone back to the national conference was we really just didn't feel that there was anything really in

our area where we felt really comfortable that was sending out a positive message. We were going through all sorts of hoops and loops trying to navigate through systems. It was very confusing.

JOHN: Everyone was telling us we need to go to this therapy and that therapy and spend 80 million hours each week.

KAREN: And I'll admit, I mean in the beginning, it's like you're told, "OK, you have this window. And you need to be able to get all of this done by then."

JOHN: You need to change your diet. You need to change everything.

KAREN: And here I am. And we went to support groups and were hearing this and this. You need to start changing this and this and this. And I take a lot of things very literally. And I'm thinking to myself, if they're saying I need to do it, and it's coming from a doctor or it's coming from someone who's a professional, I better do it. And I mean it wasn't until later I started thinking, "Well, that really just doesn't make sense. That's going against logic and intuition for me." But I was still in the mentality of I better kind of follow along with this. Because the literature that I was reading was all written from that model and not as much so coming from a self-advocacy type of perspective.

CHERYL: Yeah.

Starting to find information and community online

KAREN: And fortunately, I was able to find other people online and start to read some books and meet other people that showed a different way. And we wanted to be able to make sure that children and teens and adults and people in our community who were impacted by Autism in some way had an opportunity to feel good about themselves and that we didn't have to hide. It was so--

JOHN: And have value.

KAREN: --isolating.

CHERYL: You do trainings, you do panels, you do outreach, all sorts of things. The resources that you work from regularly include materials that people on the spectrum write. I would love for you to describe what you see as the main differences between resources that are written by licensed professionals and experts who study Autism and development versus those that are written by people on the Autism spectrum. And talk about what is behind your choice to use those materials written by people on the spectrum.

KAREN: For us, it's about staying authentic. And that means including Autistic and Aspie voices in all facets of the conversation. And there's a saying that's pretty popular in the disability rights community, "Nothing about us without us." Which is used to communicate the idea that no policy or any type of thing should be decided by any representative without full and direct participation of the members of a group that are affected by whatever that policy is. That would include therapies and educational trainings and so forth. The disability community tends to adopt that very much so. But it originally had, I

believe it was Eastern European ties. It involved a lot of national and ethnic and other minority groups as well that were often felt to be marginalized from different political, social, and economic things. So basically for us, as an organization from the get-go, we wanted to make sure that we were going to be including Autistic voices, individuals on the spectrum, in all facets of program development, volunteering, decision-making, leadership. This is very much unlike a lot of Autism organizations out there, some of which--that are large--that don't even include Autistic members on their Boards, very rarely within committees. And when they do, sometimes it's more of a--

JOHN: They're tokens.

KAREN: --a token feel, right? But for me, if I wanna learn about something, I wanna be able to go to who I feel would be an expert in that field. And if I wanna learn about Autism, I wanna go to people who actually live with Autism on a daily basis and understand what it's like to be Autistic and Aspie. And I realize, again, there's gonna be differences. We're not all the same. We are the sum of our life's experiences. But certainly, we need to start out with the basic component that yeah, you need to talk to someone that shares that neurology and that we can learn from that. When it comes to communication and social differences, oftentimes the materials that are out there and that are being used in the school settings and in therapies are being written by professionals that aren't on the spectrum. And so they tend to come across with an air of, "This behavior's not typical. This behavior's not appropriate. But you can try to fix it and adapt it and make it better if you do this social skills class, or if you do this therapy." I've interviewed people who've written this type of material. And I think that they have good intentions. But it still doesn't include the Autistic voice. And it just doesn't connect.

"Been There, Done That, Try This: An Aspie's Guide to Life On Earth" book

KAREN: I actually had an opportunity earlier this year to be part of a book project called "Been There, Done That, Try This: An Aspie's Guide to Life On Earth."

CHERYL: Wow!

KAREN: Great book. And I'm not just saying that because I was in it. [giggles] Because the vast majority of the people were not me [laughs]. The project was started by interviewing Autistic and Aspie adults about what were the most challenging stressors that they were experiencing in their lives, what were the areas of the most challenge. And I think there were about 16 of them. And then going to adults that were on the spectrum from around the world, men and women of different ethnicities, socio-economic statuses and so forth, and being able to put these questions to them and for them to be able to share their take on it, based on their life experience. With the idea that you put this stuff out there, and where are people going to be able to learn from? People who've gone through similar situations and so forth. And so that's the kind of stuff that we believe is really helpful to get out there. So when I do radio interviews with Autism Empowerment Radio, a lot of the people that I have interviewed are adults on the spectrum: Jennifer Cook O'Toole, who is the founder of [Asperkids](#), has been on a number of times. [Liane Holiday Willie](#), who actually coined the term "Aspie" and wrote the book "Pretending To Be

Normal," which was the first book that I actually read and related to immensely in terms of Autism within women. And then we've interviewed Stephen Shore, just a lot of different people. And those interviews tend to be the most popular. They're the most authentic and real, you know? That's why we do it. We don't do it to make anybody else feel bad. It's just that we want to be able to give the most authentic representation. And I think when it comes to topics like that, you need to have an Autistic voice. If it was a medical issue, and it was something you really did need to be able to talk to an expert in that field, OK. It's a little bit different if you're talking about going in for an injury or something, OK. But if you're talking about social and communication issues and anxiety and the different things that are commonly experienced, it makes sense to talk to people who are coping with it.

CHERYL: Yeah, and experiencing it.

KAREN: Yeah.

JOHN: What a concept.

CHERYL: It blows my mind. I know. It just blows my mind, this idea that you should not be talking to the people experiencing the thing. You should be talking to the people who picked it apart and studied it.

Autism Scouting Leadership Training Kit

JOHN: When we put together our Autism Scouting Leadership Training Kit, it was a national committee. We actually had 16 on the committee. And over half of them were on the spectrum. That included youth in scouting that were on the spectrum because they're in the program. They're gonna have the best perspective out of anyone.

KAREN: You can say, "Hey, what do you need?" Why don't you ask somebody who perhaps needs it!

JOHN: So it was interesting. People were like, "Wow, you actually included them in the conversation."

KAREN: Good for you! [laughs]

JOHN: So not only did we include those on the spectrum, but the youth that are on the spectrum because they're the ones involved in, theoretically, in the program. And so what would you like to tell your leader on how you would like to be led? Or what you need? So I think that was really important to have that perspective. And we try to do that in everything that we do. And those goes back to our organization, the core, and how it was formed. All of our Board is either on the spectrum or has a really, really close tie to someone who does.

KAREN: It might be a parent.

JOHN: But it's important for us to have that voice to be authentic. Because if you're not authentic and supporting the people that you're trying to support by having the people in the conversation, then why have the conversation?

CHERYL: Right.

KAREN: You know, at the same time though, we do our best to try to support families as well. And a lot of the people that are looking for support and really wanting to be able to help their children thrive are not on the spectrum. And we try to share information as much as we can from our perspective because we think that's important. But we also realize that it's important for them to also have mentors that are similar to them, and that that's OK. We're not competing. There's no--

JOHN: Because that's part of their--

KAREN: Yeah, they need that.

JOHN: I'm not on the spectrum myself. I have dyslexia. But that's a whole nother can of worms [giggles]. And so I come from a parent perspective. But I also come from a spouse perspective as well. I think one of the greatest things that ever happened to our marriage was the diagnosis of Karen. Because then it basically was able to identify certain triggers. Oh, that's why that happens. Oh, that's why we had those fights. That's why we did that. It put a lot of what we did into perspective.

KAREN: It really did help improve our communication. I mean, there's something really empowering about being able to know why one might be triggered in certain ways or reacting in certain ways. Especially like with things like sensory overload and just even communication challenges, not knowing why that is. And growing up hearing bad, bad, bad and different things, then you start to internalize that. And it doesn't really help one's esteem if they're thinking those types of things. Yeah, it helped us because, we better--

JOHN: I think there's the analogy where she's a Mac, and I'm a PC. What we needed was some type of translator.

KAREN: Interface.

JOHN: Interface. And that's kinda what we needed to be able to communicate more effectively,--

KAREN: Yeah.

JOHN: --even though she's a Mac, and I'm a PC. We're able to do that.

KAREN: And to realize you know what, it's OK. We still yeah, we're still able to compute.

JOHN: We use that analogy a lot of times because we're all humans, you know. We're all--

KAREN: Well, at least one of us.

JOHN: Thanks.

KAREN: [laughs]

JOHN: But you look at the different neurologies, it's kinda like a Mac and a PC.

CHERYL: Yeah, but they both still work!

KAREN: They both still work. They both have value.

JOHN: They both still work. They both still try to--

KAREN: They're both, yeah.

JOHN: They're still trying to complete the end project or whatever. But sometimes they need to communicate effectively.

CHERYL: Yeah.

KAREN: And it's important that our kids know that you may think differently, but that's OK.

CHERYL: Yeah.

KAREN: And it's imperative in a society that is sending and branding negative messaging that you let them know that even more, more often. Kids need to feel safe and secure in their own environment.

JOHN: And even the adults. And it's nice in our messaging it is actually getting out there. Because we've seen--

KAREN: Mmhmm. We've seen a lot.

JOHN: --we come by parents that go, "Oh, you know what? I think I'm on the spectrum too." And they really truly mean it. Not the token, "Oh, everyone's on the spectrum."

KAREN: Oh goodness, oh.

CHERYL: [in falsetto] "We're all disabled!"

JOHN: I know.

CHERYL: No, we're not.

JOHN: No, we're not.

KAREN: No. And it's sort of like I think they're saying it, again, thinking oh, I can relate with you and all of this. But then it's almost like, "Oh yeah, but you're not really Autistic because we're all on the spectrum."

JOHN: But we are getting these people that really do believe they are on the spectrum, and they are as adults. And they're coming to the realization where, oh, I can really function better if I have whatever I need. And it's OK to come out and say that, "I'm Autistic," or "I have Autism," or "I have Asperger's."

People can be afraid of coming out as Autistic

KAREN: And we really want that. I mean that's some of the reason that we wanted to be able to do our podcast and different messaging and for people to be able to hear and go, "Hey, it's OK to talk about

this. It's not bad," you know? A lot of people who have been afraid to because they didn't know what their spouse or their parents or their kids or their coworkers, what anyone would say, would they really be accepted? The more that we can continue to have these types of conversations and to engage people and to try to change that mindset, I really--

JOHN: Try and meet them where they're at--

KAREN: Yeah, meet them where they're at.

JOHN: --to help them get to where they need to be.

CHERYL: Yeah.

KAREN: We really want to be able to bridge the gaps that are in the Autism community and become stronger. And realize, I think sometimes parents will feel like we're minimizing their struggles. Again, we're not competing. It's not a competition of suffering. The Autistic people that I talk to, by and large, we really do, as a whole, want to be able to help the children that are growing up. And we think that we might be able to do that, not from an arrogant standpoint but from a compassion standpoint, from an empathy. We want to be able to help children thrive.

JOHN: And an inclusion model.

KAREN: An inclusion model, yes.

JOHN: I think the inclusion model's so important because--

KAREN: Absolutely.

JOHN: --it's beneficial to everyone involved. It's beneficial to those that have the disability because they have peer mentors. And then the people that don't have the disability can be more sympathetic or understanding of maybe challenges or issues that are going along. So we're trying to really change a whole generation. If we can change that generation to really understand that it's about inclusion and acceptance, that it's gonna bring up everyone.

KAREN: I think it's really important for kids in classroom settings and so forth to be able to be, everybody to be included together. I think they will learn from each other. And it seems to me that a lot of the little ones are more accepting. At least our children have always been included. In pre-school, it was a special education pre-school. But then, once our youngest transitioned into Kindergarten, he went into a mainstream classroom with pull-outs for different types of things like speech and OT and things like that. But it was important for us to maybe go into the class and be able to talk in an age-appropriate way. You know, just kind of explaining a little bit about Autism in a way that his peers would be able to understand, where it's not a bad thing to talk about. It's OK.

CHERYL: Right.

KAREN: Really, it's all right.

JOHN: It's funny cuz we did that, and I think when he was in Kindergarten we did that. We went and read a book about Autism. And Ryan totally gets his Autism. I mean, he's totally accepting. Very, very young age, he was like, "I'm Autistic," or "I have Autism." He always jokes with mom, "Mom, you don't have Autism. You have Asperger's." [laughs]

KAREN: Oh yeah, yeah.

CHERYL: Get it straight!

KAREN: Yes, yes.

JOHN: "But you don't have Autism. You have Asperger's."

CHERYL: That's really cute.

Talking about Autism in our son's class

JOHN: So when we went to the Kindergarten classroom, we said we were gonna go. And we talked to him about it.

KAREN: Yeah, we wanted to make sure he wouldn't feel--

JOHN: Feel OK with it. And he was like, "That's fine." He goes, "Can I sit up front with you guys?" And so he sat up front, and--

KAREN: And he participated in the presentation and helping--

JOHN: --participated.

KAREN: --and even talking.

JOHN: But I remember that whole thing still very clearly. And then one of these little girls raised her hand and goes, "I have a cousin who has Autism." It starts that conversation. It's like yeah, it's OK. Let's be accepting. We all know someone, or we may know someone. And let's try to be accepting and bring up the whole.

KAREN: Yeah, or if you see oh goodness, it looks like he's having a--

JOHN: A challenge.

KAREN: a really hard day and a challenge, OK, maybe be it would be a good time to kinda get him into an area where he can have a break. Or just to be able to understand this might not be the time to be going up and talking and doing extra types of things. It's so important to have inclusion. It's interesting cuz with scouting groups, some of them are--

JOHN: Disability only.

KAREN: --some are disability-specific. And we actually had started out really briefly helping to support a group that was like that. And they were doing good things. But we soon realized, well, it would really be great for them to be included in a typical pack. And so that's where we ended up transitioning to. I think a lot of times there's fear from parents. It's like, "Oh, well, is my child gonna be able to fit in? Are parents gonna be able to understand? Maybe they may understand in a school setting. But oh my goodness, is this gonna work?" And there's a lot of fear and shame and concern on parents' ends that their children won't be accepted, or they'll be looked at as the bad parent. Why can't you control your child? And so sometimes I think people make those decisions because it's more comfortable for them, not necessarily cuz it's in the best interest of their child.

CHERYL: Oh, sure. Yeah.

KAREN: But you know.

JOHN: The group that I lead, I have 10 boys, 3rd to 4th graders. And five of them are on the spectrum, of different degrees. It's really interesting to see the dynamics and the growth of all of the boys. I mean, not just the ones that have the disabilities, but the ones that don't have the disabilities helping everyone else out. And to us, we keep very clear is, again, there might be a special circumstance for these other types of groups. But whenever possible, inclusion needs to be the real model.

CHERYL and KAREN: Yeah, yeah.

JOHN: And I think a lot of times, "Well, you don't have value because you have this or that or whatever."

KAREN: Or, "You can go to this level but not here." And I'm like what? Are you kidding me? And that's why a lot of times, "Well, you just must not have it that bad. You know, you've had a career. You've done this and this. Therefore, you must be OK. Well, you look fine to me!" And in some ways it's like you start to doubt yourself. Well, what? Are you asking me to suddenly show off my challenges so that you can respect the fact that I might be on the spectrum? I mean, it's so confusing!

CHERYL: It's so confusing! And it's so contradictory because if you show signs or symptoms, I don't wanna look at you. You need to go away. That's weird.

KAREN: Yeah.

CHERYL: But then, you tell someone, "I'm hiding part of my identity right now so that we can talk." "Well, blah blah. I don't see them." "Well, but that's because you demanded that I hide them!"

KAREN: Yes, yes.

CHERYL: "And you called them signs and symptoms, when really to me they're part of me and my identity and how I do things. So which do you want? Because if I show it, you're gonna gawk at me. If I don't show it, you're gonna tell me I'm making it up, and I'm over-blowing." And it's just--

JOHN: Or you don't get it.

KAREN: There's no win.

CHERYL: You don't get it.

KAREN: There's always a lose-lose situation.

When experts say we don't seem disabled

CHERYL: It's very lose-lose. And I find it in the brain injury community too. I cannot tell you--not because I don't want to but because I cannot remember--how many people tell me, and they mean this as a compliment, "Well, I never woulda known you had a brain injury if you hadn't told me." And I'm like, first of all, this is not a compliment. You are dividing me from my peers.

KAREN: Yes, yes.

CHERYL: Second of all, what the [bleep] does that mean?

JOHN and KAREN: [laugh]

CHERYL: And it's like. And so then what they're doing, they're putting me in this trap to make me prove myself. "Well, let me tell you what year it happened and how many impairments and how many rehabs I had." Soon as I go home from this interview, I'm going right to sleep. I'm going to crash.

KAREN: Right.

JOHN: Karen does the same thing.

KAREN: I need to decompress from that.

CHERYL: You can't help it. Your system goes into overload. And also, cuz you're putting forth this extra effort to appear somewhat normal and presentable. But I know people who've had worse injuries than mine who are less impaired. I know people who have had milder injuries than mine who are extremely disabled from it. And so when you say, "You don't look like you had a brain injury!" what you're telling me is you don't actually know anything about us. It's the people who have the highest credentials who will say this.

JOHN: And they've never experienced it.

CHERYL: They're trying to show off how expert they are by saying, "Well, you don't fit my typical criteria that I have in my head when I give my diagnostic gaze to people on the street."

KAREN: [laughs]

CHERYL: "I don't believe I'd diagnose you that way!" But it's not a compliment. "You guys, you're so good. You're smart! How could you have that?"

JOHN: "Oh, good job for you!" [laughs]

KAREN: "Good for you!" [laughs]

CHERYL: "Yay! That's so special!"

JOHN: "You accomplished that!"

CHERYL: So where is this? When people tell you, you can't possibly be Autistic because you've accomplished great things, they're showing that they have not spent five minutes in the community looking at the culture and looking at the very real contributions of all types of all people. We're actually talking about humans here. And this whole, "I gotta box you in and label you and fit you. And you don't fit my picture. So therefore, you're lying--"

KAREN: Yes!

CHERYL: "--or you're mentally ill and you're delusional." It blows my mind constantly how much this happens and how "You look fine" is a compliment. "You don't look like you have a disability. You don't look like you have a difference." What does that mean?!?!?

KAREN: I know, it's so tough, Cheryl.

CHERYL: Awful! It drives me up the wall.

KAREN: It is.

CHERYL: It's divisive.

KAREN: It is very divisive.

CHERYL: There are people who can't see brain injury as a culture or a community. They can't see Autism as a culture or a community. And therefore, they assume it's all about badness and brokenness and wouldn't you want to change it?

JOHN: Or they don't want necessarily to be associated with that community because then they have to admit something that there might be something "wrong" with their family. And it's about them and not supporting the person that does have Autism.

KAREN: And John, actually you make a really, really good point there because there's a lot of genetic ties in Autism. A lot of adults will find out about being on the spectrum because a child, a grandchild, a niece or nephew or someone's been diagnosed. And as they learn more and educate themselves more about it, they realize oh, yeah.

JOHN: It's kinda like me. They don't wanna have to put that mirror up to their own face.

KAREN: And they're not ready to. Because they hear back stuff about it.

CHERYL: Right.

KAREN: So it's like, well, no, there's nothing wrong with him because that might mean there's something wrong with me. And they're still thinking that wrong, wrong, wrong.

CHERYL: Right, and I know that your organization and you're interested in saying this isn't about wrong.

JOHN: It's about right. It's like acceptance.

CHERYL: Acceptance, yeah.

KAREN: And understanding.

JOHN: Blowing the ceiling off your trajectory.

CHERYL: Yeah.

KAREN: It isn't about saying, "Hey, we're just all gonna stay in the same place." It would be arrogant to say that there aren't challenges.

JOHN: Absolutely. And you still might need supports.

KAREN: Yes. But let's get those supports in a way that's gonna be meaningful.

JOHN: Having the supports in place as a child and then having the supports as an adult, I know some adults that they're incredible workers. They have supports. Their employers understand their value and understand the value of putting in supports to give them the best chance to succeed.

KAREN: Yeah. I mean I think accommodations.

JOHN: Accommodations are OK.

What do people know about Autism?

CHERYL: What do people know about Autism? What do people think Autism is, in your impression?

KAREN: That's really tough because I mean in the past, they'd go, "Oh, it's something to do with 'Rain Man,' Dustin Hoffman, you know everybody's like that. Oh, I met somebody with Autism once, therefore, everybody with Autism is like this." There's a saying in the Autism community from Dr. Stephen Shore that if you've met one person with Autism, you've met one person with Autism! Which basically means it's not one size fits all. It's a spectrum. It is a neurological difference. But it's not going to present the same way from person to person. And there's a lot of range. And it will present differently in men and women, in children, teens, adults. And some of the individuals that are on the Autism spectrum are non-verbal. And that's gonna present differently than somebody who's verbal. And so it can be really tricky to try to explain all of the intricacies in just one type of question. People tend to have impressions based on what they've heard and read and seen in media. And unfortunately, a lot of times that's negative, and Autism's an epidemic. Autism needs to be cured. This is the potential cause for Autism. Oh, if you had only taken this vitamin or eaten this food or done this or that, maybe your child wouldn't have--

JOHN: Or vaccinations.

KAREN: Yeah, I mean there's so much in the media that goes around the negative. And so it's very, very hard for people who are advocating for themselves who are not even allowed to be able to identify themselves. And I say that because there is a lot of controversy within the Autism community on what we're allowed to call ourselves. A lot of adults on the spectrum will say, "I'm Autistic" or "I'm Aspie." And that's for Asperger's Syndrome. Or you know some people will say, "I'm on the spectrum." For us personally, and what we advocate, is that people have the right to be able to define who they are and to be able to say, "OK, I identify as Autistic. I identify as Aspie" or whatever.

JOHN: If you got into like a school setting, they may say you can't identify a child as Autistic because that's not what's called people-first language.

KAREN: Yeah, I mean there's people-first language, which generally that's something that shows up in the educational setting, in the medical system and so forth. And I think that there's really good intentions with it, in the idea that yes, we wanna put the person first and not the disability. So ideally, I think people when they're talking this way, they have good intentions in terms of wanting to respect the individual. But when it goes to the point where people are telling you, "Oh no, you're disparaging yourself by identifying this way," then it doesn't make sense anymore. And so we always tell people that people-first is really more about tone and about attitude and about respect--

JOHN: And intentions.

KAREN: --than it is about linguistics and semantics. And intention. I've had people come to me and go, "Oh, you really shouldn't say that. You really shouldn't call yourself that cuz you're putting yourself down." And mm, you know, it's very confusing. It's like, "Well, why would you think I'm doing that?" And it's because of what's been put out there that this is something really negative, it's an epidemic, it's bad, it's something to I guess feel shame about in some ways. Not everybody feels that way. But that's the impression that comes across a lot of times. In the past few years, violence was associated with Autism, whether it be a person on the spectrum that was being murdered by a parent who wasn't able to deal with their particular situation, or whether it was perceived as a person with Autism suddenly had a mental break and ended up hurting someone. There's all of these stories that get this press that give an impression of Autism which isn't really the day to day experience that most people on the spectrum have.

JOHN: And then people become fearful. Is that person dangerous? Are all Autistic people dangerous? Well, no. [laughs] That's ridiculous. Everyone's not the same. Everyone has different circumstances.

CHERYL: Yeah. It's interesting, that whole if you've met one person with Autism, you've met one person with Autism. That comes from that sort of minority model of identity. You know, when 9/11 happened, I even had a family member of mine say, "Well, what do you expect from muslims?" I'm like OK, well, I'm not actually going to engage with that question.

KAREN: Oh, yeah.

CHERYL: But why is it that this one group of people, however large or small the group that orchestrated 9/11, why are they now the representatives of all muslims?

JOHN: Everyone.

KAREN: Yeah.

CHERYL: When a white, straight man, say, goes into a movie theater and murders a bunch of people, we don't say, "White men!"

KAREN: Oh my goodness.

CHERYL: "They always! You see? What could you expect from white men?"

JOHN: Right.

CHERYL: You don't hear the mainstream media say that, yeah.

JOHN: Absolutely.

CHERYL: But when start to get into different religions that are not dominant here, different ethnicities, skin tone, gender identity, mental illness: "See? All of them." "I met this one Autistic kid who was so violent. So I don't want any Autistic people around me ever." Well, hang on now!

KAREN: Yes.

JOHN: Or I met this one immigrant that did this one bad thing.

CHERYL: Right.

JOHN: Doesn't mean that all immigrants are bad, cuz everyone else shouldn't be all lumped together.

CHERYL: Yeah, yeah. And we do that when we have a group that seems to be a minority, we just lump them all together. You all must be like that.

KAREN: Yeah, it's so frustrating.

CHERYL: It's so damaging. You've talked about media in different ways. You talked about, say, maybe promotional videos that are put out by an organization.

KAREN: Oh goodness, yes.

CHERYL: And you mentioned "Rain Man," which would be, maybe a fictionalized....Although, of course, that individual didn't actually identify as Autistic. But there's a little detail that we like to just ignore. So there's the news, there's fiction, there's non-fiction. And I feel like what you're saying and what I've experienced is that overwhelmingly most of what's out there is the negative, in terms of media: this epidemic. We gotta cure it. They're dangerous. They're scary.

Putting out a positive voice and positive message

KAREN: Autism Empowerment, there're other organizations, ASAN, there're ones that want to put a positive voice and a positive message forward on behalf of the Autism community in whole. The organizations which get the most donations, if you look at the 990s, by far are ones that are putting out the crisis message, epidemic message, and feeding into this is a real struggle, this is really hard, we need to fix this, we need to cure this, this is horrible. And honestly, I believe that probably the vast majority of people that work for different organizations do have a good heart and good intentions in mind. Unfortunately, there are some people who make choices that don't include Autistic people in the conversation or believe that that voice is an integral part of actually serving the Autism community. And I disagree with that. But I feel that the more that positive messaging comes out, hopefully that that's going to give an opportunity for people to change their way of thinking and realize that it's not about trying to exploit people to get a donation. It's about trying to help people live a better quality of life. Most money, in terms of donations and where the money goes tends to go to parent-led type of organizations. And we're parents of children on the spectrum. So I'm not against parents. [all laugh]. I just wanna clarify that.

CHERYL: Oh, all those parents! You've met 'em!

JOHN: They're all the same!

KAREN: Those darn parents. Right? They're all the same. But I--

JOHN: They're coming from, a lot of times, from a place of crisis.

KAREN: Yeah.

JOHN: And they're trying to fix something. Or I guess a lot of times, they have an issue or challenge that their child has displayed. And they're trying to manage that. They don't understand that in Autism there's what's called the Autism grief cycle, a lot of times. And understanding that cycle is really important cuz if they can understand that the cycle will happen over and over again, I think that's important.

CHERYL: Yeah.

KAREN: For Autism Empowerment, our four pillars are accept, enrich, inspire, and empower. So when we talk about acceptance, I think a lot of times, people that are kind of new into the diagnosis or they're having some challenges, really legitimate challenges, they can't even conceive what acceptance might be. I totally get that because as John talked about earlier, there is an Autism grief cycle that people go through. And that's OK. Acceptance means being able to, in our view, to accept people for who they are, where they're at, at this point in time. And that may mean accepting them in a position which may not be ideal in terms of positivity. But that's where you're at. And it's being able to say, "OK, I've got this. Now let's move forward." It's not Pollyanna. We're accepting! Yay! Now everything's OK.

JOHN: [laughs]

CHERYL: Yeah, that's fine. Yeah.

KAREN: We're all OK. No. Earlier today an article came out by John Elder Robison, who wrote the book "Look Me In The Eye." And he talked about how most Autism research right now is all wrong. There's tons of money being poured into all of this Autism research. So if that's the case, then why are most adults on the Autism spectrum unhappy with the results, and why are things really not going the way that one would think, based on the money? And he commented along the lines that it's because by and large, Autistic adults and individuals on the spectrum are not being included in the conversation in terms of what kinds of research would be helpful and beneficial. It's addressing a model that looks at cure versus this is a life-long disorder and a neurological difference. And the focus also being so much on childhood when 75% of people are going to be adults.

CHERYL: [giggles]

KAREN: And the children that are out there, yes, we want them to be able to experience the best quality of life possible. But they are going to grow into teens and into adults. And so it's really important for organizations and researchers to look at that from an oh, this is a difference model versus ok, we need to find a cause and a cure.

Research with answers the Autistic community already knows

CHERYL: Yeah, and you know just today, I was reading something on an activist's blog. And this person was reporting on research that came out in 2013 that, guess what? You're gonna be shocked.

KAREN: [laughs]

CHERYL: Maybe you already read it, and then you won't be shocked. But it turns out--they discovered in 2013--that in terms of Autism, there's not a lack of empathy.

KAREN: [laughs]

CHERYL: We've always thought oh, well you can't empathize.

JOHN: There's too much.

CHERYL: There's too much empathy.

CHERYL: Ok, so I looked over. I didn't read the whole thing. But I read the comments on Facebook. And all the commenters said, "...Duh. You could've asked me that 30 years ago, and I woulda told you that's my experience."

JOHN: And probably save millions of dollars.

KAREN: Oh, absolutely.

CHERYL: And this idea that what you have to do is take an Autistic person and do these tests and then say, "That's what it is! It's that brain function. It's that cognitive skill."

JOHN: Or it's this gene that causes this. So we need to fix that gene.

CHERYL: Right.

KAREN: Mhmm.

CHERYL: But in the meantime, what about parents who can't afford resources or don't know how to get them or can't afford an internet access to be able to log on and listen to your radio show?

KAREN: Right.

CHERYL: And you got this money going to these genes, empathy.

KAREN: Absolutely.

JOHN: Or culturally, if the information's not in Spanish or Russian or any other language that these populations are being--The thing about Autism is, it's in every single population.

KAREN: Yes.

JOHN: It doesn't matter if it's Black, White, Hispanic, Latino. Doesn't matter if they're old or young. Socio-economic, it crosses every single: blue collar, white collar, no collar. Being able to reach as many type of people, that's the importance.

KAREN: Yeah, I agree with that. If there's so much infighting that's going on right now with organizations, and there's so much conflict just in general, I mean it's even harder to reach out to families where Autism is something that you just don't talk about. It's kind of hard to explain. But I think a lot of times, when you hear "Autism," it's associated as something's wrong with you and not something's different. I facilitate in a group for adults on the spectrum. And we talk about different types of things where it's very difficult a lot of times for adults to come out and talk about being on the spectrum or that, "Hey, I'm Autistic." They don't wanna be able to say it because they feel that immediately people are gonna look at them differently. And when they look at them differently, it isn't gonna be different like, "Ok, you have a difference." It's gonna be, "Oh, something's wrong with you. And something's bad." The more that that's put out there by other organizations, hey we're raising money to cure this or to fix this or boy you guys really, really have it hard, and you know they're talking about the struggles of the parents. And they're not saying, "Hey, let's really improve the quality of life for people and work with the challenges that they have. It's more on a disability model in terms of a medical wrong. And it's just really, really tough. You constantly see in the media how certain organizations are just able to constantly raise millions and millions of dollars on this crisis-epidemic model.

JOHN: And then the funding, there's only a very small portion of all of that funding that actually ends up going back to service individuals.

CHERYL: Right.

KAREN: I don't wanna go trashing any organizations.

JOHN: Absolutely not.

Connecting communities

KAREN: And just for full disclosure, we had our Autism and scouting program developed a few years ago. We believe that scouting's a really good opportunity for kids, teens on the spectrum. We've seen that with our own boys and many, many children that we've worked with. And we wanted to get training that we were working on developing and this idea to be able to go through scouting units throughout the country. And so we had applied for a grant with Autism Speaks. And at the time, people were saying, "Oh no, don't do that. It's gonna go contrary to what you believe in." And I said, "Well, I think it's really important that we try to build bridges and let them know that programs like ours do exist and that they're coming from a self-advocacy model." And if they don't accept the grant, then they don't accept the grant. But they did choose us. As a result, we had to have their logo as that they're the funding partner for this. You know, we developed it, we wrote it, everything that was done in terms of the development of the curriculum was all on the Autism Empowerment side. But there's that logo, which brings a lot of mixed feelings for people. And they make an automatic assumption that well, you must believe this and this and this. And it's not that way at all. It's just a matter of having an opportunity to be able to do good. If we don't agree with certain philosophies within an organization, OK, well, let's come to the table. And let's try to talk about it more. Because I believe that there's a lot of things that other organizations do that do have good intentions, that there's good within. There's things I definitely would change. I really think that in order for our Autism community as a whole to grow stronger, we have to be able to have all sorts of different opinions at the table.

JOHN: It's connecting the communities together.

KAREN: It's truly connecting communities together. And if we isolate ourselves and focus on all the disagreements that we have, then as passionate as we may feel, we're still going to be perpetuating disruption. I don't think it's right in any way, shape, or form for kids and teens to hear negative branding and messaging on TV about Autism. For adults either; it's triggering. If you grow up hearing, "Oh, this is bad, this is an epidemic," you internalize that. And for people like myself on the spectrum who tend to take things very literally, I can abstract from it, and I do. But when I was younger it was not so much that case. And so if I hear "bad" with "Autism," I associate it as I'm bad. And a lot of kids are hearing these types of messages. And sometimes their parents are saying these types of messages right in front of them. Children that are non-verbal, sometimes people make assumptions that oh, you're non-verbal. Therefore, you're not listening, and you can't understand, and you don't know what's going on. And so it's OK to talk about you in a negative way in front of you. And it's not. Never. If you don't invite people to the table to have a conversation, even if you know that you're coming from a different point, you're not going to be able to, I think realistically make change.

JOHN: I think it's also reaching out to other communities outside of the Autism community as well.

KAREN: Mmhmm.

JOHN: The whole disability community because what might be working for another organization with a different disability might be able to benefit the Autism community as well. So I think being able to connect with other organizations that don't maybe seem to be connected, maybe ultimately there might be connections.

Cross-disability work and acceptance for all

CHERYL: Yeah. Tell me about some of the groups that you have done cross-disability work with.

KAREN: OK, so we've done a wide range of different things. Cuz we really believe in inclusion, not segregation, right? And so yes, we want to include cross-disability. Ideally, we'd like to include everybody, you know, right? We do a lot of different panels. We do an annual bullying prevention panel and Unity Day panel. Most of everything that we offer, I mean it's pretty much open to anybody who wants to be able to come. We have probably our biggest event, which is a cross-disability collaboration, is our annual Easter Egg Hunt for Acceptance of All Abilities.

JOHN: And most people think oh, it's an Easter egg hunt. And yes, it's an Easter egg hunt. But to us, it's much more than just an Easter egg hunt.

KAREN: It's an acceptance event.

JOHN: It's an acceptance event of all abilities.

CHERYL: Yeah.

JOHN: It happens each April or right before Easter, depending where that lies. And what we do is we actually rent out a football stadium.

KAREN: McKenzie Stadium.

JOHN: McKenzie Stadium here in Vancouver. And we actually line the sidelines with cross-disability organizations. In 2014, we had 40 organizations. With that one day, we actually were able to serve 1400 people. We had government agencies, such as police department, the fire department. We had [The Arc of Clark County \(Southwest Washington\)](#), [Parent to Parent Coalition](#), [Amazing Moms](#), faith-based organizations. There was even [Autism Society of Oregon](#). So again, reaching out to other Autism organizations, making sure--

KAREN: [Special Olympics](#) came.

JOHN: Special Olympics was there.

KAREN: And a wide range. We invite pretty much anybody who we feel might be interested in coming.

JOHN: The event starts with a national anthem. And the color guard is typically made up of individuals who either have disabilities or have Autism or some type of disability because again, that's why we're bringing the community together. And then after that, we have local political leaders actually roll out the first egg. And we do that not because it's like, oh look at us. Look who we've got here.

KAREN: Mm-mm.

JOHN: It's more about we want the political leaders to say, "Look at our community. And this is our community." Please help us in bringing our community together and bringing us the services that we need. It's actually made an impact on several state legislators in their attitudes in the state House.

KAREN: People will lobby, and people will come up and meet with us. But being able to come out here for a few hours and actually be immersed in the community, that's more impactful. You see that we're just all human beings.

CHERYL: [giggles]

KAREN: And oh, there's no horns. [All laugh.]

Segregation and media representations

CHERYL: Well, and that's the thing. Like you said, we do still have segregation in our society. And then you've got the media representations that there is this diagnosis that needs to be eradicated, which translates to, we should never have any more people like that.

JOHN: [laughs]

KAREN: Yes.

CHERYL: And like you said, how could you not internalize that at least a little bit?

KAREN: Yeah.

JOHN: And I think when we say, "that," that means those people are putting themselves above other people.

KAREN: Mmhmm.

CHERYL: Absolutely, and that's part of segregation.

KAREN: Yes.

JOHN: Right, and to get rid of "those people" or "that," that mentality is really hard to change the culture. But it's ultimately a society we're striving for. A lot of times during the event, we're running around doing a million things. A lot of times we hear feedback. One of the coolest stories was we had one of our partners say that this mom had a child that just had this huge meltdown. And everyone

walked by and just smiled at the person. And the mom just felt that it was OK that that child was doing what they were doing because they were being themselves.

KAREN: Yeah. I mean, come as you are. Let your light shine. You can be accepted for who you are if you're having a good day, if you're having a bad day. You're having a challenge, if you've having a success. The shirt that John's wearing: it's a dark green shirt, which is one of the colors of Autism Empowerment, the color of Acceptance. And on the shirt there is a globe in a shape of a heart. And it says, "Ambassador for acceptance of all abilities." And this is the shirt that we had all of our volunteers wearing at the event. And so when people came in, they saw this wherever they looked, pretty much. We had about 170-180 volunteers. There was somebody around here who's wearing this shirt. And the idea is OK, I'm accepted. I'm going to be accepted here, whatever that might look like. And it's so important for people to be able to see those messages, cuz it's not what you see normally.

CHERYL: No, it's not.

KAREN: And it's empowering. And we always tell people when they come to the event, "You're an ambassador for acceptance of all abilities. You are today. You are every day. And that you have a choice to be able to go home and be an ambassador for acceptance in your home, in your community, and to always be able to share that message." Because truly, it's the message we want our children to grow up feeling, adults to be feeling. It transcends just disability. It's just general life, right. People wanna be accepted and respected and valued. And we all have gifts and strengths. I think that the more messaging like that, that talks from a positive angle and really focuses on strengths, the better it's going to be for all of us in terms of being able to work forward.

CHERYL: Well, the other thing I heard in your story, John, is not only was that child accepted: Oh, that child's having a meltdown, maybe because this is a big, overwhelming, over-stimulating environment, not cuz that child is broken. But I also heard you talk about that parent was accepted as they are.

JOHN: Right.

CHERYL: Because I know you hear the stories, and I hear the stories of "Why can't you control your child?!"

JOHN: Right.

CHERYL: "You're not a good parent!" "Well, my child has Autism, and this is what he 's going through." "Well, nah nah nah. Back in my day, we didn't have Autism. We just had bad kids! And we just disciplined them!"

JOHN and KAREN: [laugh]

JOHN: Absolutely.

CHERYL: And it just spirals out of control. And what is a parent to do when everyone's against them?

KAREN: Yeah, yeah.

JOHN: And the parent went up to this other person and said, "Thank you for having this event because I can just be myself. And I can let my child be themselves." And people weren't looking like they were a bad parent. They were looking like, "Oh, I understand where you're coming from. I've been there myself." And so they were met with smiles and sympathy.

KAREN: Well, and compassion.

JOHN: And compassion, absolutely. And empathy.

KAREN: Yeah. I think it's--

CHERYL: Wait a minute! You guys aren't supposed to have empathy!

JOHN: [laughs]

KAREN: Oh no, no.

CHERYL: Wait a minute. I read this article. I read this study--

KAREN: [laughs]

CHERYL: --that Autistic people don't have empathy.

KAREN: [gasps] Yeah, we don't have humor either.

CHERYL: No, you don't.

KAREN: Did you know that?

CHERYL: So that's happening here?

JOHN: [laughs]

KAREN: I don't know.

CHERYL: What's going on?

KAREN: [laughs] I think we must've eaten the right breakfast cereal, and suddenly it developed. [laughs]

CHERYL: I know! You're not really Autistic! That's what it is, right?

KAREN: That's it! Oh my goodness.

JOHN: Because Karen's communicating coherently.

KAREN: Oh gosh.

CHERYL: Yeah.

JOHN: Therefore, she could not be Autistic.

CHERYL: No, she couldn't be.

You don't have it that bad. You're not really Autistic.

KAREN: No, no, no. No. And you know what? You bring up a point. I mean people go, "Well, you must not have it that bad. You're not really Autistic. I mean, you can, you know, talk, right?"

CHERYL: Where'd you get your PhD in all this? I'm like, what?

JOHN: You don't know what I go through.

KAREN: Yeah. Yeah, well, I mean, John you bring up a point, which is really important to is that in the Autism community, there's a competition of suffering sometimes that goes along. And it's like you know--

JOHN: You don't have it that bad.

KAREN: And honestly, I mean I understand that people have a wide range of complex challenges that go on in their lives. And I wouldn't dream to say I've walked in your shoes because I haven't. But at the same time, it doesn't really serve for us to be competing with our tragedy. Let's work together and see how we can move forward. We're kind of in a unique position. I mean being Autistic myself, being a parent of children on the spectrum, and also being a professional, I'm in this position of sometimes riding the line between self-advocacy groups and parent-led groups. The tough thing is sometimes it's like parents, oftentimes, they need to feel support, especially moms. I am very active in terms of following groups online, Autistic culture: both self-advocacy and parent groups. And so you can get a feel for basically themes that come up over and over again. And I think a lot of times, parents especially, when their children are young and relatively new to diagnosis, they're really focused on that I need to try to get this taken care of as soon as possible. They don't really think to say, "OK, it might be really kinda cool to actually talk with some adults that are on the spectrum and see. They must've been kids once. See maybe what their take is.

JOHN: Or they put them in a box, they put their kids in a box, saying, "Oh, they'll only ever reach to this level."

CHERYL: Cuz someone told them that.

KAREN: Yeah!

JOHN: Because they'll never amount to much past this, rather than we believe in blowing boxes away--

KAREN: Huge trajectory, yeah. Positive trajectory.

JOHN: --and imagining--even if your child is non-verbal--imagine the best possible life for them. Dream big for them and shoot for the sky. If it doesn't get there, at least you're shooting for the sky and not shooting for the basement.

KAREN: I think a lot of times people spend all of these hours working on OK, what therapy's gonna work, what's this and that. They mean well, right? They want to be able to help their child, especially if they see their child like experiencing what they perceive to be pain and different things like that. I get that. I mean, but spend time with your child and try to get into their world. And I think that rather than just focusing on social skills types of things where you need to try to change your child to adapt into a neurotypical world, they're never going to be. They're just never going to adapt into that. For myself personally, when I grew up, I always felt a sense of difference. And I could script and learn and memorize and watch and observe different people and change my behavior to try to pass. But it was exhausting.

CHERYL: I wonder why the burden is always on...us to pass. And one of the things that you're advocating, and again, you're not doing it in a contentious way. But rather than have society sit and wait for Autistic people or whoever to assimilate, or at least pretend to assimilate, if we're truly gonna be accepting of all, then we all have to flex a little bit.

JOHN: Absolutely.

KAREN: Yes.

CHERYL: And so, if I can't make eye contact, you could maybe just deal with that, right?

KAREN: Oh yes. Oh my goodness, yes.

Lack of eye contact isn't disrespect

JOHN: It's funny, cuz we had that exact conversation this morning about eye contact. There's so many times in society, "Oh, you need to look at me, or you're disrespecting me." No. It's OK if you're not looking you straight in the eye. He's trying to process it more effectively by not looking you in the eye. [laughs]

KAREN: Yeah.

CHERYL: Absolutely.

KAREN: I mean for my personally, it's sensory overload. As it is, I hear all sorts of different conversations and things going on at the same time. If I'm trying to process that and the intensity of eyes and all of these different things going on, I lose my train of thought. I can't listen. I can't be as effective in speaking and engaging. So it's not to be rude, you know.

CHERYL: Of course!

JOHN: But some teachers and leaders and parents will see that as a sign of disrespect.

CHERYL: They see it as disrespect, but I think what's the bigger thing in Autism, is they see it as a sign of abnormality. "Normal" people look each other in the eye.

JOHN: Right.

CHERYL: And every time you do whatever you're doing instead of looking normal, you're showing off that you're abnormal and disabled, and that's not OK. So stop.

JOHN: Or different.

CHERYL: Or different.

KAREN: Yeah, yeah.

CHERYL: And again, I don't say that to criticize any individual person. But these are the messages that we get, that "normal" people look each other in the eye. Normal people communicate in this way. That is the message that, as a culture, we give people. And so again, what is a parent to do when their child is doing something that they were not expecting, and they think it's wrong? Make the child stop doing it that way so that they're normal and accepted! I would like to see more people be more accepting of different communication.

JOHN: And different is not bad.

CHERYL: It's not bad.

KAREN: Yeah.

JOHN: It's just different!

JOHN and KAREN: [laugh]

CHERYL: Well that's the thing. And we, especially liberal people love diversity, right? Oh! Bring on the different languages and the different music and the food and the culture. Oh, disability? Mmm, don't. No, don't bring that.

JOHN and KAREN: [laugh]

CHERYL: That difference isn't OK. Why is that person rocking?

JOHN: It's too uncomfortable for me.

CHERYL: For me, yeah.

JOHN and KAREN: [laugh]

JOHN: Maybe once you change, then come back. And then we'll talk.

CHERYL: Then we'll talk. Then I'll have a potluck with you. But I just--

JOHN: With all the languages and the culture and everything else.

CHERYL: Exactly. And it's something that really blows my mind. It goes back to things that you were saying before, Karen, where people will tell other people how they should identify themselves. And people say, "You shouldn't say you have a disability. You shouldn't say you're disabled. No, Autism is this! I define it. I decree!"

[All laugh.]

CHERYL: Wait a minute.

KAREN: In talking with a number of adults on the spectrum that are just coming into acknowledging this for themselves, they're afraid to be able to talk about that because of the messaging that they hear.

CHERYL: That's right.

KAREN: And even like within their own family. And also, as John mentioned, again grief cycle: anger, denial, bargaining, all these legitimate emotions that people are feeling and going through before they can actually get to a point of acceptance, that stuff's going on at different points in time with their family members.

Autism grief cycle and expectations

JOHN: To speak to that just a little bit. In a typical grief cycle like, for example, when someone dies, well someone's dead. They're not gonna come back to life. And there's a finality to that point. So you go through the grief cycle. You get to that final stage of acceptance or whatever. And then you can move forward. In Autism, a lot of times when parents get a diagnosis, they're like, "Will they ever be potty trained?" Well, then the next one, "Will they ever make it through school? Will they ever go to college? Will they ever get married? Will they ever leave home?" I mean, so the cycle just continues on and on and on, continually. So that's why when we say the Autism grief cycle, it means it could go on for a whole lifetime in some cases.

KAREN: Yeah, I think kinda what you mean there is when we're talking about it in that context, parents have preconceived ideas of what they expected their child to have in terms of things.

JOHN: Expected them to grow up, go to college, get a nice job, and meet someone, have grandkids.

CHERYL: Right. Well, that's because we're told that's the only valuable life course. How often do you hear, "Oh, thank goodness it was a healthy baby!" You can get the amniocentesis and different testing. From before children are born, we have already ranked the ones who are potentially gonna be valuable, and the ones who are not likely to be valuable. And we don't even realize the weight of our message when we say things like, "Thank goodness it was a healthy baby." What if you're talking to the parent of a child who was born with significant disabilities? You just said, "Thank goodness my kid's not like yours."

JOHN: "Not like you."

KAREN: Yes.

CHERYL: And it's meant to be positive.

JOHN: My family's better than your family.

CHERYL: My family's better. Shwew! But the issue is not that the child is born with disabilities. The issue, I think, is all the opportunities that are going to be denied that family from the instant that child comes into the world, and the biases against them. I don't think our society thinks about all these obstacles and all these structural and attitudinal things that are gonna happen. It's just, "Ew. Oh, that. That's ew."

JOHN: "That poor family."

CHERYL: "That poor family. That child."

JOHN: Rather than, "Oh, how can we lift up the family and make sure that the family can have the best possible life?"

KAREN: Yeah, thrive.

JOHN: Thrive.

CHERYL: Lift up the family.

KAREN: Yeah.

CHERYL: Include everyone! Let's see. Let's go over this, here.

JOHN: Invite them over for dinner. Or invite them over for a bar-b-que. Be inclusive.

KAREN: Or, if that person says--

JOHN: Or leave them alone.

KAREN: Well no, I mean it's a good point. And if you say to a family member, "You know, maybe we can't go to this particular type of event because it's really sensory stimulating and overloading" for the family member to then be willing to be accepting of maybe accommodating you too, and not saying, "OK, you know--"

JOHN: Or I can't travel. I can't put my family on an airplane and travel four hours to go see you just like everyone else, my other siblings have. But you know what? Maybe you could come to us.

KAREN: Yeah.

CHERYL: Everybody flex a little bit--

JOHN: Right.

KAREN: Yeah, everyone flex.

CHERYL: --where you can. But I think the important thing is that people outside of disability communities and outside of the Autism community, that people understand that they also have the responsibility and the possibility to flex. And that it shouldn't always be from within these marginalized communities that we have to do all the flexing all the time and feel guilty if we didn't do a good job.

KAREN: Oh yeah, yeah.

JOHN: And then to be ostracized.

KAREN: We train a lot of scout leaders in ways to be able to more effectively work with kids in their units that are on the spectrum. And a lot of times, some of the things they have the questions about are the visual things that they see, the stims.

CHERYL: Yeah.

KAREN: Right? The rocking, the flapping of the hands, the humming, those different types of things, flicking fingers. And it's really a matter of being able to explain to people, well it's really about self-regulation and sharing behavior. And that if we took away your coffee, or we took away your chocolate or your soda or whatever it is that makes you feel comfortable, whatever that is, how do you think that you would cope and deal? And to understand that everybody needs to have some sort of way to be able to cope and regulate. And maybe that way is a little bit different than what you're used to.

JOHN: But that's OK.

KAREN: But yeah, that's OK.

CHERYL: That's OK.

JOHN: As long as they're not hurting themselves or destructive, safety issue, it's fine.

KAREN: As long as it's not a safety issue or something along those lines, yeah.

KAREN: We talk about that mask, pretending to be normal and how exhausting that is. And wanting to be authentic to ourselves. But I mean, we've kind of grown up in a way where it's like how do you really even find yourself because you're this combination of so long scripting to try to please other people. I want people to be able to be themselves and feel that that's OK, you know?

The Loud Hands Project

CHERYL: Are y'all familiar with the book, "Loud Hands?"

KAREN: Mm-mm.

CHERYL: So [The Loud Hands Project](#): [Julia Bascom](#).

Loud hands, right? In response to "Quiet hands! Quiet hands!" Have you heard that term, quiet hands? It's like the speech therapy response to flapping hands.

KAREN: Oh!

CHERYL: "Quiet hands."

KAREN: Oh.

CHERYL: To get you to stop flapping. As if flapping is bad, which OK.

KAREN: Right.

CHERYL: So this group of self-advocates and activists came up with The Loud Hands project. And then this book, "[Loud Hands: Autistic People Speaking](#)" is an anthology of essays by people like, "Lemme tell you how loud my hands are!"

KAREN: [laughs]

JOHN: Yeah!

CHERYL: "Let me tell you how beautiful my hands are." There's a range of essays. It's a huge range of experiences. All of it comes from the perspective of "there is nothing wrong with my loud hands." And I love this book! I have recommended this book to a lot of people when they ask like, "What do you do about someone who...?" "You know it's kinda weird. Can Autistic adults ever whatever?" I'm like, "Just read this book. Because it's written by actual Autistic people."

JOHN: Right. It's authentic.

CHERYL: And rather than have me answer and speak for someone else, you just go read that book. And stop asking me what Autistic people can do because this is a population of people who have created media and writing.

KAREN: Yeah, that's true.

CHERYL: And so you don't have to sit around and ask each other. You can go to the source, which leads me to a question I had written here that I wanna ask.

Autism allies

CHERYL: So you have mentioned that everyone on your Board is on the Autism spectrum or closely related to someone who is. And you also use the term "Autism allies." The term ally is really intriguing to me. I think that we feel good about ourselves when we call ourselves an ally to someone else. I do agree with this idea that it's really up to this marginalized group to say, "You know what? You're acting as a good ally to me. You are our ally," rather than you just self-define as an ally to all these people. So in terms of Autism allies, describe what makes an Autism ally, a true ally to what you're doing?

KAREN: So authentically for us, I believe that Autism allies are people who are accepting and respecting of youth and teens and adults on the Autism spectrum, and that they support our vision as an organization of an inclusive society that respects all youth and adults on the spectrum and empowers

them to reach their highest potential. To go a little bit further with that, an ally isn't someone who just purchases a pin and says, "Hey, I supported Autism Awareness."

CHERYL: [chuckles]

KAREN: That's not--OK, I'm not saying that's bad. But what I'm saying is that we're about acceptance.

JOHN: Actually shows acceptance.

KAREN: We want you to be genuine. We don't want you to be a poser. I think a lot of times people, oh, well, we'll accept that cute little kid with Autism. But you know that adult over there? Nah, not so much.

JOHN: He's wearing a big, fuzzy jacket.

KAREN: Nah, not so much.

CHERYL: Yeah.

KAREN: It's OK cuz that child with Autism's pretty quiet and nice in play. But that one's making a lotta noise. And I just really don't wanna have my child near them or something.

CHERYL: That's not an ally.

KAREN: Yeah, that's not an ally. It shouldn't be conditional, right? It should be unconditional.

CHERYL: Yeah.

KAREN: And to me, an ally is someone who says, "OK, let's work together and figure out ways that we can better accommodate you, better serve, better understand." It's someone who's willing to admit, "You know what? I really don't know as much as I'd like to think I do. And why don't you tell me about so-and-so." Or, "You know what? I notice that you've been talking about having challenges with sensory. And I really don't get that. What does that mean?" It's like genuinely wanting to get to know people within the Autism community and accept that we are human, you know? Does that make sense?

CHERYL: It makes perfect sense. And I also hear in that, that it's not just wanting to know about people on the spectrum, but from them--

KAREN: Yes.

CHERYL: --from your voice. Not, "Oh, I better go find a textbook on sensory overload and sensory integration therapies. Let me just ask this human who's with me," right?

KAREN: Absolutely. Yeah. And I think a lotta times--

JOHN: Lemme look it up online to see what the experts say. [laughs]

KAREN: People will do what makes them feel comfortable and good. Sometimes we'll post content. And it'll be meaningful content--that we feel is meaningful! Ah, this is really good. And it'll get a couple likes

here and there, shares or what not. But then you'll see someone who posts just this little picture of I don't know, just--

JOHN: A cute little kid.

KAREN: You know well, just basically I think sometimes people feel that they're supporting Autism like when it's just like, "I'm a Superhero!" Or "Kids with Autism, they're just so Superhero-ish!" Or whatever [chuckles].

CHERYL: Right. But it's from a distance.

KAREN: It's from a distance.

CHERYL: They're posting memes and pictures and buying pens and doing little token things that they can share with others, "Look. I supported this."

KAREN: Yes!

CHERYL: But are you--

KAREN: Do you really?

CHERYL: Do you really? Would you really hang out with that kid in that picture? Or do you just think it's cute because it's in a picture, and you don't actually-

[A baby cries in the next room]

CHERYL: There's the kid from the picture!

KAREN: There's the kid. There's the kid. Unfortunately, there are people that just are not that compassionate and understanding! But they like to think that they are. And it's very important for them to show that they're supporting. It would be unfair for me to say what their real intention and motive is. I can think what I have an idea of what they're thinking. But yeah. I guess again, an ally. I mean, I want someone that I can have an authentic conversation with that's willing to be able to talk about complex issues and willing to go beyond the fluff. And it's not just about--

Small talk can be confusing

JOHN: Well, I laugh cuz you talk about fluff. A lot of times we'll get into these conversation where the people are like, "Oh, how are you doing? Oh, the weather's sure--" They'll do all of this non-substance type talk. Do you really care about how I feel? Or are you just saying that because that's just a conversation starter?

KAREN: OK, so a funny true story on that: So in high school it was always like, you know you go down that hall. It's like, "Hi, how are you?" [mimes the person walking away] And then I was also so confused because I thought they were asking "How are you?"

CHERYL: [laughs]

KAREN: Imagine that! So I wanted to actually tell them how I was. But by then, they were already gone. It was like, huh? You know?

CHERYL: That is really confusing, yeah.

KAREN: And picking up on those types of slang and social intricacies and all of these unspoken curriculum rules that are not intuitive to many of us on the spectrum.

CHERYL: I'm hearing this. And I'm thinking also, part of this must be about dropping your preconceived notions. Now remember, people on the spectrum have terrible social skills--

KAREN and JOHN: [laugh]

CHERYL: --impaired communication, can't empathize. You're walking down the hall. And someone says, "Hey, how are you?" but doesn't actually stay for the answer? And **you're** the one with the communication impairment?

KAREN and JOHN: [laugh]

CHERYL: I am being light-hearted about this. But the point that I'm making is--

JOHN: Cuz it's so true.

CHERYL: --is that we have this preconceived notion in our culture that it is fine to make small talk in general: "Hey, how's it going? Oh my gawd. Oh, it's raining! Ugh, it's cold, ugh!" And you walk away, and that it is totally socially acceptable. And yet, when you encounter someone who wants to actually answer the question and go deeper because it sounds like a real question, you have an impairment. I don't understand why that's an impairment. Somebody asked how you're doing. I get what you're saying. But the preconceived notion that small talk is good. That's a universal, right? No, small talk is not universally good. Maybe some people like it, some people don't. But we have this idea that small talk is good and that being literal and answering the question that was asked is impaired and bad. They're not universally true. If authentic for you means I'm gonna damn answer that damn question because you damn asked it--

KAREN and JOHN: [laugh]

JOHN: You better be willing to take the response.

CHERYL: Yes, take the response.

JOHN: That's an ally.

CHERYL: Yeah. And don't have to like get your panties in a wad over it. You asked!

JOHN: Yeah, exactly.

CHERYL: And why does it have to be Karen's problem that she answered, when you were the one who asked? And I think because we have the preconceived notions that you've got the label, so your communication is flawed. I don't have the label, so my communication is never flawed.

JOHN: So I can be rude and not really care [laughs].

KAREN: And it won't count. [laughs]

JOHN: And it won't count!

CHERYL: Right. Cuz I have empathy, and you don't.

JOHN: But if you're rude to me, well, that's you're impairment!

KAREN: Oh!

CHERYL: Oh! Disabled people: they're so rude. They're so rude.

JOHN: Those Autistic people are gosh, my gosh.

KAREN: Oh my goodness.

JOHN: Why can't they just understand and communicate better.

CHERYL: And why can't she just overcome it?

KAREN: [laughs]

JOHN: Why can't she just not care? Because I really don't care how her day was.

CHERYL: Isn't that interesting?

KAREN: [laughs]

KAREN: Yeah. I really don't care. But I'm gonna ask you.

CHERYL: And we talk about the Autism community being people who are rigid.

KAREN and JOHN: [chuckle]

CHERYL: OK. So. Just saying.

Accessibility plugins on Wordpress

CHERYL: I have this thing called the AT Bar on my website. It's like this assistive bar up top. But you have these other access features. Users can choose to toggle between a high contrast version (where the background will turn black, and the words are white and yellow) or the more average contrast with the dark words on the lighter background. People can choose a color version of the website versus black and

white. They can change the font size. And I wish all websites had these features. Tell me why you have those features on your website.

KAREN: We want our website to be accessible to everyone. To be truthful, if we could do more, and we had the technical expertise to be able to make more accessible options, we would. Because how can we build an inclusive society if we don't include everybody?

CHERYL: What?

KAREN: Hmm.

CHERYL: No, no, there's gotta be an answer to that!

KAREN and JOHN: [laugh]

CHERYL: There has to be an answer to that.

KAREN: We wanna try to be open to everybody to be able to come and read. And obviously, that's limited somewhat to our technical expertise and so forth. But we think it's very important for people to have those options. And that's also why we try to do trainings and share information in a variety of different formats, to try to reach people where they're at. It's why we try to work with different groups, different cultures to be able to meet them where they are and to learn more about them as well. But in terms of the accessibility for our site, our website at [AutismEmpowerment.org](https://www.autismempowerment.org) is Wordpress-based. And there's a free plugin called WP Accessibility, written by Joe Dolson, that people who have a Wordpress-related site can download for free.

CHERYL: The AT Bar that I use is a different plugin. But I'll probably use your plugin too. And now I know the name of it.

KAREN: Yeah.

CHERYL: Great.

KAREN: And so it's free. And there's a couple other features that go along with it. I wish, ideally, I could have it translated as in many languages and being, not just a translate literal, but a linguistically appropriate translation. I mean truly, that's something we, as an organization, are really trying to strive and work towards, is making sure everything's accessible.

Learning Together Connecting Communities

JOHN: That's why what's exciting is [the grant we're all a part](#) of is being able to get with people like [IRCO](#)--

KAREN: Learning Together Connecting Communities.

JOHN: --and some of these other groups because it helps us in our community grow.

KAREN: Yes!

JOHN: And it helps, again, the overall community be lifted up.

CHERYL: Absolutely.

KAREN: Yeah, I'm learning a lot. I learn a lot from other communities by talking to them. It's just like I would think that they would probably, if they're not on the spectrum, they would learn from me, talking to me, from my perspective as I would learn from them, talking about whatever particular perspective they're coming from.

JOHN: It's like our Easter egg hunt. We had a martial arts demonstration, right? But what we would love to do is have a dance demonstration.

CHERYL: Ooh! [DACP](#), yeah, oh!

KAREN: That would be awesome.

CHERYL: For the ADA 24th anniversary, the City celebration, Disability Art and Culture Project was there. And not only did they do two performances on the stage, but they had a dance off competition!

KAREN: [laughs]

What's in store for the future?

CHERYL: So you've got different trainings, you've got [the scouting programs](#), you've got [Autism Empowerment Radio](#), which has a huge listenership. What's in store for the future from Autism Empowerment?

JOHN: Well, it's kind of exciting cuz we just were going through our 3-5 year strategic plan. We have long-term goals. Eventually, we would love to have a center here in Vancouver that not only serves Vancouver but serves regionally and nationwide.

KAREN: Yeah, we see ourselves as growing into a national organization. Truly, a lot of the stuff that we do already has a little bit of reach. The radio program, that can be accessed and listened to from wherever anyone has those accessible methods. And the scouting program: that training is currently being used in 50 states. But really, we want to be able to have these positive messages of acceptance and teaching empowerment to be throughout the country, throughout the world. And we do anticipate, a lot of times, piloting programs, perhaps in the Southwest Washington/Portland Metro area and making sure that we're very loyal to our community. We do a lot of community outreach. We wanna make sure that people within our community know that we're here. But where we see ourselves a lot of times is as more of like an educational type of an organization. We do a lot of different types of things in terms of outreach. Like John mentioned, we'd done the egg hunt. We do these sensory-friendly play days and events. We did a movie in collaboration with Mass Mutual where it was a sensory-friendly lights-up/sound-down movie, which was pretty awesome.

JOHN: We'll hopefully do another one in 2015.

KAREN: Yeah, we'll do one in 2015. We do panels. We try to basically see, OK, what does our community want and need, and what are they missing, and what can we do with our resources to be able, as much as we can, to be able to help along with that.

JOHN: Some of the other cool things that we're looking to do is doing a mentorship program. But that's kind of in the works.

KAREN: So one of our programs that we hadn't mentioned yet was our Autism Service Volunteerism Program. And that's basically inclusive volunteering. It includes volunteer opportunities for individuals that are on the spectrum, but also opportunities for families and other community members to volunteer alongside. And that's an area we wanna build out a lot. There seems to be a huge need for people to be able to connect with people that can kinda relate to their circumstances. And in the Autistic community, that may not necessarily take the form of a one-on-one type of mentor. A lot of times, people can benefit from a wide variety of different types of experiences. So we're working with our Board to try to figure out what's the best way. If we need to develop something online, have different types of components locally, in different communities throughout the country. We just think it's important when people are out there seeking support that they're able to be able to connect with someone who's gonna be able to relate and be able to connect with them. But at the same time, realizing that's not gonna be necessarily the same person for the same topic and so forth. So that's kind of one of the big things down the road. As John said, we really would like to have a Center of Excellence here in Southwest Washington, sort of a national hub.

JOHN: National headquarters.

KAREN: Yeah, people will look at us sort of like that, "But you can't be Autistic, you know this and that. You can't have all these big dreams!" I'm a big vision person. I think in these big visions. And I have Post-Its and all of these types of things. This has been a calling for me. And I really want to make sure that people know that we're, as an organization, we're here to stay and that we're here to positively move forward, and to be able to talk about addressing the topics that are difficult within our community. I did a blog recently and also a show on Autism Empowerment Radio talking about Autism community: is the notion of that even possible to really strengthen? And I think we're going to be trying to include and engage people on the spectrum throughout the area and throughout the country in talking about some of the difficult things that are going on and how we might better bridge the gap and be able to have organizations that are fighting, work together better. And if they can't work together, then how can we somehow get a message out to families whose children are getting diagnosed that it's not the end of the road. That it's actually the beginning of a journey that is going to have lots of twists and turns. And it's gonna be a path that you might not have initially expected or anticipated. But life is rarely what we anticipate or expect.

CHERYL: Absolutely. So with that, with letting folks know that you're an organization here to stay, and you're well on your way to becoming both a hub and a headquarters--

KAREN and JOHN: [laugh]

CHERYL: --tell folks where and how they can find you online, on the air, in Vancouver.

Where to find Autism Empowerment online

KAREN: So we encourage you to visit our website at www.autismempowerment.org. You can also connect with us on Facebook: facebook.com/AutismEmpowerment. If you go to our website, up in the upper left-hand corner, there are different icons for the different social media places that we're connected, which include Facebook and [Twitter](#) and [Pinterest](#) and all of those good places, [LinkedIn](#). Our offices are currently located in The ARC of Southwest Washington Family Center, which is 6511 NE 18th St. in Vancouver, Washington, 98661. The phone number you can reach us at is 360-852-8369. John can be reached through email: john@Autismempowerment.org. And I can be reached through email at karen@Autismempowerment.org.

CHERYL: I would really like to thank both of you so much for telling me all about this organization and the work that you do. It's my huge pleasure to get to know you two a little bit better and have this conversation.

JOHN: It's our pleasure as well.

KAREN: Thank you so much, Cheryl.

[music]

CHERYL: Thanks for joining me for another episode of Stories from the brainreels. Find more handy info on brain injury and disability art and culture on my disability arts blog, WhoAmItoStopIt.com.

[music]