35th Annual SPIN Conference

October 23, 2021

**Autism Networking Room Q&A**

**Speakers:**

Jeffrey Krepps - Autism Society of Hawaii (ASH)

Debbie Kobayakawa - Ho‘omana Parent to Parent Support

Kiele Pennington - The Autism Community in Action (TACA)

Renee Manfredi - Self-Advocate

Michelle Manfredi - Parent

1. Autism Society of Hawaii (ASH)
   1. Social Group “Advancing our Futures”
   2. Gamers Club (statewide) for those who like role-playing games
   3. Dad-to-Dad group
   4. ASH Book Club
   5. Learning Series: workshops throughout the year
   6. Sensory-Friendly Films
2. Ho’omana Parent to Parent Support
   1. Parent-led, parent-run group, funded by the Windward District Autism Program
   2. Virtual, statewide program, open to any family, any disability
   3. 1:1 coaching
   4. 3 meetings a month, 1 meeting has a guest speaker, 2 meetings are talk story sessions
3. The Autism Community in Action (TACA)
   1. Local zoom meetings
   2. National parent support meetings
   3. Facebook support
   4. National conference
   5. Quarterly presentations about when a child becomes newly diagnosed can be helpful to families

* Comment: My child has a hard time expressing his feelings verbally; instead he takes them out on objects around him. He does not have a definite diagnosis of ASD, but it is suspected. We live on Hawaii island.
  + Parents were encouraged to get a diagnosis, so the child can get support and interventions as soon as possible.
  + Talk with other parents, to find a psychologist to get a diagnosis.
  + Intense interventions work well for kids to get the most out of their life.
  + LD/ADHD Center of Hawaii may travel to neighbor islands for appointments and getting a diagnosis.
  + Ask your PCP for a recommendation. If they refer you to a physician on Oahu, insurance may pay for transportation costs.
  + Remember that when doctors say “high functioning autism” it doesn’t mean they have “less” autism. An autism diagnosis means the child has autism, regardless of where they are on the spectrum, and interventions can be very successful.
  + ABA in a non-clinical environment can be helpful and empowering to the child.
* Question: Is there a difference between kids who are deaf/hard of hearing and have autism, and kids who only have the autism diagnosis? Do you use PECS picture system for communication only, or do you use ASL with the students too?
  + Yes, you can use PECS with the sign language. Use PECS as a supplementary tool to whatever language the child and family use daily. Yes, you can pair them.
  + When choosing a communication mode for any child, consider having an assessment done to see what communication mode they prefer. You can work off of their strengths and not with a communication mode they choose not to use.
  + Texting can be another mode of communication individuals can use.
  + Some kids like to use ASL to communicate, because it allows them to process just the one language quietly, where sometimes vocal language can be overwhelming. It’s very direct, very clear, and the child does not have to process and filter out sounds.
  + Remember that interventions and communication can look very different from one person to the next; it is important to individualize their interventions and communication strategies.
  + I wish we would have known about sign language when my child was small, because that may have been a simpler road than verbal language at the time.
* Question: What about for kids who may speak using words, but may not communicate in a way that others can understand the context or meaning behind the words?
  + When my child was in early intervention, we focused on using less words to get the point across, like “no run” because there is less to process and you can get the point across easier.
  + One of my barriers is that I’m considered “high functioning,” so I don’t get related services because of that. In a quiet, calm space, I can put my thoughts in order and communicate. But when questions are rapid fire, or there is a lot going on around me, it can be very difficult to find the right words to say or to answer questions, because it’s too much to process.
  + I often don’t qualify for services (though I could benefit from them), because I am often able to communicate or manage my day-to-day needs, and the professionals will say “oh, you don’t need any help at all, you’re doing great.” But the truth is, they tend to overestimate what I can do and what I understand. Yes, I can communicate. I can speak, but it does not mean I don’t need help.
  + When I was in school, and I didn’t understand something, I would cry, because I did not know how to say “I don’t understand, I need help.”
  + Kids may not bang something, or throw something, to show their frustration with communication, sometimes it comes out in a different way, like quietly crying in the corner.
  + It is frustrating for me, as an adult with autism, because I can communicate. Someone might pummel me with questions, or people talk really fast and assume I understand what they are saying. I ask them to slow down and tell them I have a disability, I am autistic, and they say, “really? You don’t look autistic.” That is a frequent comment.
* Question: As an adult self-advocate with autism, do you have a person with autism that you look up to or respect? Do you have any leaders or mentors that help you grow in your advocacy?
  + I know self-advocates through SSIGM, the Sargent Shriver International Global Messengers, who have different disabilities from all over the world, and I look up to them. They are my group.
  + With my daughter, she is obviously impacted by autism, requires total care and she is a signer, so people “see” her disability. My son, who is “high functioning,” struggles just as much in his own way. Other parents would say “oh, he’s easy, at least you have one easy one,” and I would say, it’s not that it’s hard and burdensome, but it does take as much effort. He needed as much of my attention, support and to get services as my daughter did. It looked very different, and the supports were different, but in doing that, he was able to do more of the things he wanted. And because people didn’t see his disability, they would put on all these labels on top of him that were not true. He did have a processing issue and he did have fine motor issues with handwriting, so he was scolded so much about why he couldn’t do things--that he was bad and not compliant, which was not the case. He just needed more time, and more opportunities to hear things or get sensory input for himself and he thrived when he was in the right situations.
  + I would encourage parents to not look at the levels of the diagnosis, but to push forward to meet the needs of your child, and look forward into the future. When my son was in lower elementary, he was able to accomplish a lot. When he moved into upper elementary, there were new rules, new social situations, new ideas that he really struggled with. Folks wanted to jump off, because he had done so much in the lower grades, but we had to keep on it, and fade in services and fade them out again, as needed.
  + I appreciate that so much, because one year, the school wanted to take away my child’s IEP, and that was really all we had to give her supports at school. The school would say “she’s fine,” but she was not fine. She was struggling in school, relationships were challenging and she didn’t fit in. Even today, and she is an adult, sometimes we have to go over conversations we have with others, who don’t believe she has a disability. And when that happens, it feels like a slap in the face, like I’m always having to prove or convince people that I have a disability and I need help. Some IEP tests were like “hey, don’t forget you have a disability” and I’d be like “ya, it’s kind of hard not to.”
  + Yes, it is like a slap in the face. It feels like the more success we have, the more we have to prove when we need help. And we have to keep talking about my son’s disability, and he personally does not want to talk about it. And now, as he’s more successful, people want to dismiss it or not want to acknowledge it, or even say he never had autism. It feels like we have to speak about it more often than we should have to. We are trying to get him to open up more about what he needs – not about his disability – but what he needs, as any other person would.
  + Yes, the reason I let people know I have a disability in the first place, is so when we are having a conversation, and I may say something out of the blue, that has nothing to do with the topic whatsoever, I can avoid that look that other people will give you that says “ok, what’s wrong with you?”, they would know. Then they tell me “don’t be so hard on yourself” or “don’t sell yourself short.” In other words, they don’t believe me.
  + I’m just going to put this out there: how many of you have heard of Temple Grandin? She’s one of the most famous people with autism; she has a PhD in Bovine Science, and she is a classic example of a very intelligent, bright, articulate woman, who has struggled with autism her entire life. She wrote a book about her life called “Thinking in Pictures” and a book called “A Thorn in My Side” that she wrote with her mother. To me, nobody has the right to challenge anything. It’s nobody’s business but your own. Autism is such a spectrum, and it’s not something you can see. It’s a set of certain characteristics and you can go to one professional to get a diagnosis, and go to another professional and not get one.
  + Even if you cannot get supports from the medical or government agencies, most people have amazing natural supports in their families and friends around them.
* Question: How do you explain how autism affects a person to your child with autism?
  + Renee: I didn’t learn about my autism untiI was 13 or maybe younger. My mom explained to me I was handicapped. I understood what handicapped meant. I took that into consideration. It wasn’t like a bombshell, but it explained a few things like why no one wanted to play with me or why no one wanted to be around me. It was something I took unto myself. When a new school year would start, I would ask my teachers “are you aware I have this disability and I need help?” and they would say “yep, we know, we already talked to your parents” and I would be okay with that.
  + Michelle: My memory is a little different than Renee’s. I wanted to protect Renee. I don’t remember telling her she had a handicap, but maybe it was a bad day and maybe I did. We eventually had to have that conversation, around junior high, about how she thinks differently from other people and things are harder for her to process. In 9th grade, we had to really talk about her having autism, and what it looks like for her. I don’t know that we did it the right way. There wasn’t a lot of groups or support back then. Today there is a lot more talk about autism, where you can glean information from other parents. We just looked at it from the perspective of “this is what we are, this is where we’re going, this is how God made us, and we’ll be the best we can be.”
  + Renee: I will confess that my disability was a barrier and I hated it for a while, because there were things I couldn’t do like my friends, but I would say that the one struggle I had was that we were a military family and we would move from place to place. And for a long time, I thought I was the only person in the world that was different. My senior year, we moved back to the U.S. and I was in a SpEd program, and I looked around at the other kids like me and I thought “wow, there’s more?” Fast forward, I joined Special Olympics, and I am literally surrounded by others and I thought “whoa! Here’s where I fit in, here’s where I belong, thank you God!”
  + Kiele: Our decision to tell our son was different, but it came around the same time period, when he was struggling in late elementary with social rules and other changes that happen around that time. We decided, with the school psychologist, that it was time to tell him. He had been mainstreamed from kindergarten with no supports, in a private school, and no one knew he had autism. We decided to do a full psychological exam to see where he was at that time, and to figure out what kinds of supports he needed. It was difficult for him because he has a sister with autism who looked vastly different than him. He understood that she has autism, but he wasn’t thinking about it as a spectrum. Through TACA family and sibling events, he was able to see other kids with autism, and see that they had unique needs and supports just like he did. That helped him to understand it, be okay with it. From there we talked about how he wanted to represent himself as a person with autism.
* Question: Renee, are you in college?
  + Renee: No, I tried taking a math class in community college. Then I became the president of a self-advocacy group, and that became my main priority for a while. I tried again later, with an English class, and I was nominated as a Sargent Shriver International Global Messenger (SSIGM), and I put college on the back burner, because to me, being in the SSIGM is a little like being in college. SSIGM is an athlete leadership position for Special Olympics. I am a public speaker and Special Olympics messenger, all over the world. There are 10 of us from all over the world and each of us have a different platform. My platform is “Inclusive Health.”
* Last Thoughts:
  + Kiele: I would encourage families to join a support group to connect with others in the community.
  + Michelle: I would echo that. I would have loved to be able to chat with other people and learn from them. When I was connected to other parents, I felt that I was finally not alone. It can be a lifesaver.
  + Debbie: I’m going to say that the best resource for everyone, across the board, is other parents. We (parents) get it. We may not have the same experience, but we’ve shared in similar experiences. We get it and we understand. Also check out the DD Council (Hawaii State Council on Developmental Disabilities). It’s open to all, so parents can attend too. For all of you who are here today, you’ve found SPIN, so you are well on your way to finding other resources.