



# HUSSMAN INSTITUTE FOR AUTISM

## Keynote Address at Howard County Autism Society “Pieces of the Puzzle” Gala

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### **John P. Hussman, Ph.D.**

*Dr. Hussman is the Executive Director of the Hussman Institute for Autism, and the parent of a young adult with autism.*

“A while back, my wife and I went to a Washington Capitals hockey game with some friends. We’re walking out of the stadium and I see a woman on the sidewalk, slumped against the building in the cold. It’s something we see too often, and as we walk, I reach down and press a bill into her hand.

My wife Terri is walking behind us, and she sees what happens next. The woman looks up, confused, as if she is re-living every life choice that led to this moment, and she silently mouths the words “What the hell was that?”

Terri catches up to me and says, “Honey, I don’t think that woman was homeless. I think she was just a drunk fan.”

### ***Internal-external***

Very often, we make assumptions about people based on what we see externally. That’s a problem for people with autism, because in addition to challenges in communication, social interaction, and behavior, people with autism often describe a gap between what they experience internally, and what they’re able to demonstrate externally; what they can imagine doing or saying – what we call “ideation” – and what they can actually execute with words or movement. Sometimes they become so discouraged that, as Alberto Frugone, a young man with autism said “I ended up retreating from actions.”

That gap between intention and action, between ideation and execution, is why it’s so important to presume competence. What people with autism are capable of feeling, experiencing, learning, and understanding may be very different from their ability to demonstrate. We always have to remember that we shouldn’t limit access to opportunities, information, or inclusion based on someone’s ability to pass a test. Instead, our responsibility is to presume competence, and then find ways and create opportunities to help them to demonstrate that competence.

Last week, the mother of a boy with autism wrote us with something her son shared with her. He explained how hard it can be to speak. Talking about his challenging behavior in school, he said, "It means I feel bad, angry. I want to say, please help me, but my mouth doesn't work. Words don't come out." Talking about difficult interactions with friends, he said "I want to play differently. I just can't get my body to do it. I see a picture in my mind how I can play with them, like I think of throwing them a ball, but I can't get my body to do it right away. If *you* start throwing a ball, my body will repeat it after you. It's easy when I see it."

Here's a child who has been excluded and even restrained because of his challenges with communication, social interaction, and behavior, but what he needs most is to be understood. Sometimes the first response to unexpected behavior is coercion, like a line from *Rawhide*: Don't try to understand 'em, just throw that rope and brand 'em (get 'em up, move 'em out, ride 'em in)

### ***Help me understand***

I think one of the best skills a parent can learn, is to be able to gently and non-judgmentally ask "Help me understand." That question goes a long way with typical kids too.

When my daughter was 10, she was a junior bridesmaid in a wedding. I was out of town at a conference, and I get a frantic call from a member of the wedding saying "Julianne doesn't want to walk down the aisle. You have to *make* her do it." I get on the phone, and I tell her, "Bunny, I can't make you walk down the aisle, but can you help me understand?" She answers "I was supposed to walk down with my cousin Katie, but they changed everything and now I have to walk with some weird old guy I don't even know." In her little head, "weird old guy" applies to any stranger over 20, and she needs to walk with a friend. The good thing is that my daughter has a soft spot for all things cute, so I tell her, look, imagine that there's a little nest on his head, and there's a little bird in there. You're really walking down with the little bird – the guy is just transportation. She giggles, says ok, and everything works out fine.

So we can look only at the outside, at behaviors, at what people demonstrate, or we can find ways to understand them, to meet their quiet needs, and to see them for who they truly are.

### ***I'm your friend***

With social relationships, it's often said that people with autism aren't interested in friendship with others. Yet what we actually hear from people with autism themselves is that they'd love to have friends, but sometimes it's overwhelming, and they're always the ones who are expected to change. So we see a lot of effort to teach "social skills" to people with autism. But just as important is what we teach typical children, and what we teach ourselves, which is that friendship with a person with autism doesn't have to look like any of our other friendships. They might involve a few minutes of interaction at a time, or activities that aren't typical, or changing the rules of the game. They may involve more intention, or holding up our end of the conversation because the other person has difficulty holding up theirs. There may be fewer

smiles and more unusual ways of expressing joy. What matters, though, is valuing others as they are.

When my wife Terri was at NASA, she worked with a woman who was deaf, and Terri really wanted to communicate with her. So gradually, the woman taught Terri sign language. One year, she invited Terri to a Christmas party. Terri brings a gift, and as she's handing it to the woman, she feels a rush of embarrassment. Because the gift she's picked out for her friend, is a music box. The woman opens the gift, sees Terri's embarrassment, and tears well up in her eyes. Because she realizes how Terri sees her. She signs to Terri, "I'm not your deaf friend. I'm your friend."

How many people with autism would love to say something like that to us? We move in that direction every time we presume competence. We move closer every time we see a behavior and think, not "how do I stop this behavior," but instead, "how do I understand this person, and help them meet their need." We move closer every time we hold up our part of the friendship, and allow those friendships to look different, because we see our friends for who they really are.

By being here tonight, by learning more about autism, by supporting the Autism Society, all of you help to move the world in that direction. Thank you for being here tonight, and we hope you have a wonderful evening."