



Dr. Geraldine Dawson

Setting the Research Agenda for Autism Speaks

An interview by Diane Twachtman-Cullen, Ph.D., CCC-SLP



DTC: First and foremost congratulations on your new position as Chief Science Officer for Autism Speaks.

GD: Thank you very much.

DTC: Please share with our readers how you first became interested in autism.

GD: When I was in high school, there was a family that lived across the street that had a 10-year-old daughter and twins with autism. The father had a terminal illness and was on dialysis. His wife would take him for treatment on the weekends a long distance away, because dialysis machines were few and far between. I would take care of the family on those weekends. So, that was my first exposure to autism.

DTC: Was it then that you decided to go into the autism field?

GD: Not really. When I got to college, I studied developmental psychology and planned to do research on normal development. My first clinical rotation in graduate school was at the Child Development Center at the University of Washington, and my first case was a child with autism. It just completely captured me—first intellectually, then emotionally. I made a commitment to it [autism] at that point and ended up doing my doctoral dissertation on autism. After that I did a post-doc at UCLA, and then went on to take a faculty position at UNC [University of North Carolina at Chapel Hill] because of the TEACCH program. And, I guess, the rest is history! So, I got bitten by the autism bug at a very early stage.

DTC: I can relate to your use of the word *capture*. That's how I've always described my entry into the field. Shifting gears here, I understand that you're not only making a big career decision, but also a very big personal one—a move to Chapel Hill, North Carolina. Please tell us a little bit about how you came to that decision.

GD: Well, as you know, the corporate offices for Autism Speaks are in New York, so when I was considering taking

this position I was trying to come up with a solution that would work for Autism Speaks and also for my family. The point was made during my interview that a move anywhere on the east coast would be acceptable because it would just be a short commute to New York. That's when it dawned on me that we could return to Chapel Hill. We've always thought of Chapel Hill as a second home because we have so many friends there. So, we just felt like that was a place where we could really be comfortable, and I'd be close enough so that I could work at Autism Speaks.

DTC: New York being just a *direct* flight away, I see what you mean! Is your position at Autism Speaks a full-time position?

GD: Yes it is. That, of course, was the big courageous step for me—to leave academia, having had a tenured position and having been a full professor. I felt in my heart, though, that it was the right move. I was very much attracted to being able to work on a broader scale—on bigger projects. There is just such amazing potential at Autism Speaks, so I was very excited about moving into a new position and doing something different; getting out of my comfort zone.

DTC: What will your duties and responsibilities be at Autism Speaks?

GD: Well, in my position as Chief Science Officer my role will be to oversee the science mission and strategy, so I'll be working closely with the science staff. We've got so many great people. I'll be working with them, as well as with the various advisory groups and stakeholders to develop the scientific vision and strategy for Autism Speaks. You know, of course, that we have a grants program that is an important component of that.

DTC: I do. We've actually reported on the grants program in ASQ. Can you give our readers a sense of the road ahead?

GD: Sure. We're very interested in investing in areas that we feel have the potential to really change the field and accelerate

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the science. So, we're working on developing a strategy for how best to do that.

DTC: There seems to be a controversy among people about genetic research versus treatment-oriented research, although I'm thinking that it shouldn't be an "either-or" thing. Is it fair to say that you will be, in essence, and with input from lots of people, kind of determining what percentage of time and monies would be used for, say, genetic research versus that which is treatment oriented?

GD: I wouldn't use the word *determining*, but I would definitely say that I hope to help shape the strategy and priorities. I don't really see a focus on genetics versus, say, environment versus treatment. I don't see those as mutually exclusive. They're really all part of the puzzle, and we very much need to put resources into all of those areas. Some of the work that we're currently supporting in the area of genetics has the potential to help us discover medical interventions that could profoundly change the course of lives for individuals with autism. Similarly, trying to understand whether environmental factors play a role in autism is also important. For example, If we find out that sub-groups of kids are vulnerable to certain environmental factors—whether it's viral infections in the mother during pregnancy, or whether it's toxins in the environment—that could lead to the potential for prevention strategies.

At the same time we recognize that it's equally important to be conducting studies on treatments that have an impact right now. Examples are the Clinical Trials Network where the focus is on new pharmacological interventions or, the Toddler Treatment Network where we're developing interventions for infants and toddlers. So, it's not an either—or; it's really all of the above.

DTC: Yes. I think of genetics as setting the journey's agenda, so to speak, and the environment as influencing the actual journey. Clearly, there's interplay.

GD: There certainly is interplay, and I think all of those pieces are equally important. If you look on our website [www.autismspeaks.org], you'll see our four portfolios. There's one focused on *etiology*, which includes both genetics and environmental factors. Another one is focused on *biology*—trying to understand what's going on at the level of the cells, the brain, and the body. The third portfolio is focused on *diagnosis*—epidemiology, early recognition, and bio-markers. The fourth is focused on *treatment* very broadly conceived, taking into account pharmacological, behavioral, and psychological interventions, as well as treating children's medical conditions. We think things like sleep disorders and GI conditions have been underserved in the past, which may make children less able to respond optimally to some of the behavior interventions. So, it's a very broad agenda.

DTC: It certainly is.

GD: Oh yes. In fact, right now we're looking to put more resources into environmental factors, but treatment continues to be a very huge emphasis at Autism Speaks.

DTC: That's wonderful to hear. And that brings me to a hot-button topic—what I'm referring to lately as the "V" word. I'm sure you know what I mean.

GD: Yes, I do. Here's our philosophy on it. We believe that for the vast majority of kids, vaccines have been shown to be safe, and it's a very important part of our public health program to be able to prevent very serious diseases such as measles, mumps, and others. That being said, we also recognize that there could be sub-groups of individuals who may respond poorly to vaccines in some way or who have adverse reactions to them. If that's the case, then we need to understand that. We need to be able to identify who those kids are, and we need to understand the mechanisms behind adverse reactions so that we can prevent them. So for us, it's just a matter of trying to do the science that answers the questions.

DTC: I think that's very well stated. Tell me, what went into your decision to leave the comfort of your laboratory?

GD: That was, of course, the big decision, because I do love science and I've loved being in the lab. I will, however, be able to stay involved in, and bring to fruition, all of the projects I was involved in at the point at which I took this position.

DTC: Great. Is one of those the Baby Sibs Project?

GD: Yes, and several others.

DTC: Do some of those other studies have to do with experiential learning?

GD: Well, yes. One of the studies at the University of Washington is a randomized clinical trial of an intensive behavioral intervention using Sally Rogers' Early Start Denver Model. We are looking to see whether kids who receive these kinds of interventions show changes in brain activity in response to language and social information. This is important because in the past we've shown that young children with autism have atypical brain responses to social and language information which we think could be the result of not having had early stimulation of the brain systems that underlie those areas. If that's true, then by intervening early we may be able to actually alter the course of development, and we want to measure that.

DTC: Experiential learning is a main interest of mine, so that's very good news.

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GD: I do want to add that what I find most exciting about my new role [at Autism Speaks] is that I will be taking a much broader view—thinking about science from the point of view of the field as a whole—addressing such questions as where do we want to be; what are our goals; what can we do that will make the most difference for people with autism and their families; what’s the strategy from a science point of view that should be taken to achieve that. It’s like designing a study; it’s just at a much broader level. So I’m hoping to still use my research skills, just in a different way.

DTC: Yes. I see what you mean. What are your personal goals as you begin this new chapter in your life?

GD: Well, as you know Autism Speaks has merged with the National Alliance for Autism Research and Cure Autism Now. We hope that by the end of the first year we will have developed a vision and strategy for the science program. We have two different programs that are in place that have a lot of potential for integration and synergy. One goal is to create a coherent and visionary program that will have the most impact possible on people’s lives. Focusing on early detection and intervention are very high priorities for Autism Speaks. We also want to help individuals who have autism now have satisfying and productive lives, whether they are adolescents or adults. What do we need to do to help them to be successful? Some of it is also translational. We know a lot of good things that should be done, and we need to determine how best to get them out into the community.

DTC: I’ve spoken to other researchers who tell me that there is a relative scarcity of research subjects out there.

GD: Well, I do think that programs such as the IAN, Interactive Autism Network out of Kennedy Krieger, is a great mechanism for that purpose, because part of its website is devoted, specifically, to matching families and researchers, and to providing a place where researchers can explain what they’re doing. I think that it’s very important that we take the time to explain why what we’re doing is important, and what will be learned from it. I think that when you do that, families often are very motivated to be a part of research.

Also, part of attracting research participants is about good communication, and your journal is, I think, a fantastic example of that; helping parents to understand what we’re doing; why we’re doing it; and, why it’s important. Then the other is just finding each other, and places like IAN are great places for that, also, your journal again, because it provides a place for


researchers and parents to connect with each other. The better the communication between the researcher and the parent community, the faster we’ll be able to make progress.

DTC: Thank you very much. You have certainly encapsulated ASQ’s mission—that of serving as a bridge between the research and greater autism communities. Can you give us your take on the controversy that swirls around the issue of finding a cure for autism? As you know, this is particularly controversial among adults on the spectrum.

GD: Well, I don’t think it’s really my place, of course, to make that decision for another person because it’s a very personal one. If an individual who has an autism spectrum disorder is leading a very satisfying life, and feels that his or her unique perspective and way of being are gifts that should be treasured and valued in our society, well, I absolutely endorse that. So it makes a lot of sense to me that that person would not want to have those amazing qualities “cured”, so to speak. But I think we also have to acknowledge that there are many people with autism, and families of people with autism, who are not feeling fulfilled, and are struggling with serious behavioral or health problems—that there are individuals who have never learned to speak, or can’t tolerate being out in the community because of the sounds or whatever else they find troublesome. I think that those individuals feel very differently about this issue. They would like to be able to live more satisfying and productive lives. To me, the differing opinions represent the amazing heterogeneity in this condition, and it is that heterogeneity that influences the decisions each individual makes in responding to the question of cure. We have to respect that.

DTC: Beautifully stated! Please outline for our readers some of Autism Speaks’ research initiatives?

GD: Sure. In the area of etiology, there are several large studies that are still focused on identifying the autism susceptibility genes. In addition, there’s an interest in developing animal models for autism so that the causes we discover at a molecular level can then be experimentally tested in an animal model and lead to treatments. We are also investing more funds into examining a wide range of environmental factors that may be playing a role in autism. This could include anything from toxins in the environment, to viral infections in the mothers, to vaccine schedules. In the area of biology, we’re going to be focusing on understanding brain development at a much more detailed level. The Autism Tissue Program is one that we’ll be putting more resources into because we feel it’s going to be very important

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to understand what is going on at the level of the cells and the neurons. We're also going to be investing more in treatment, not only pharmacological interventions, but also behavioral interventions across the lifespan. And, we're interested in investigating complementary and alternative approaches.

DTC: Wonderful. That certainly covers a wide area. I have just one follow-up question. I think that a lot of lay people look askance at animal models. Could you please speak to the importance of animal models in research?

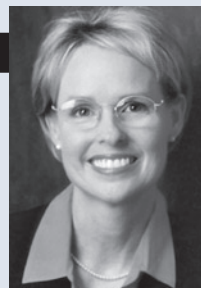
GD: Sure. Take, for example, fragile X. We were able to discover the genetic basis of that condition and then to model it in an animal by altering the fragile X mutation. What the recent discovery has shown is that we can then go back and intervene biochemically to help that animal recover from the syndrome. We obviously can't do those kinds of experiments in human beings. So, as we discover specific genes that we know can lead to autism or autism-like conditions, then it allows us to create animal models where we can manipulate the biochemical pathways related to that gene to see whether we can reverse or minimize the actual syndrome. This kind of research can lead to medical treatments for autism.

DTC: That will do it. I want you to know that this discussion has been as intellectually stimulating for me as, I'm sure, it will be informative for our readers. Thank you so very much for taking the time to speak with me today.

GD: And I thank you so much for asking me to do this. I love your publication. I always look forward to reading it, and I

BIO


Prior to becoming Autism Speaks' first Chief Science Officer in January 2008, Geri was Professor of Psychology and Psychiatry at the University of Washington and Founding Director of the University of Washington Autism Center, which has been designated an NIH Center of Excellence since 1996.



While at the University, Geri led a multi-disciplinary autism research program focusing on genetics, neuroimaging, diagnosis, and treatment. Geri's own research has been in the areas of early detection and treatment of autism, early patterns of brain dysfunction (electrophysiology), and more recently, development of endophenotypes for autism genetic studies. Geri has co-edited or authored a number of books about autism spectrum disorder and brain development, including *Autism Spectrum Disorders; Human Behavior, Learning, and the Developing Brain*; and *A Parent's Guide to Asperger Syndrome and High-Functioning Autism*. She has been widely published in academic journals. From 2000-07, Geri founded and directed University of Washington Autism Center's multi-disciplinary clinical services program, which is the largest of its kind in the northwestern United States. A strong advocate for families, Geri has testified before the U.S. Senate on behalf of individuals with autism and played a key role on the Washington State Autism Task Force.

Geri earned a Ph.D. in developmental and child clinical psychology from the University of Washington. After graduate school, she studied as a postdoctoral fellow at the Neuropsychiatric Institute at UCLA and, a year later, accepted a position as Assistant Professor at University of North Carolina in Chapel Hill. In 1985, she returned to the University of Washington as a faculty member, where she continued her research on autism and practiced as a clinical psychologist specializing in autism until she accepted her current position at Autism Speaks. She currently resides in Chapel Hill, North Carolina with her husband and daughter.

always put it in our waiting room at UW, so I'm honored to be featured in it.

DTC: I really appreciate that. I wish you the best of luck in your new position, and I congratulate Autism Speaks for having one of the foremost autism researchers in the world at the helm of its scientific "ship". 

Editor's Note: Many thanks to Geri Dawson for giving so generously of her time.

For more information about Autism Speaks, log on to www.autismspeaks.org

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