A career devoted to improving the lives of people with autism

Geraldine Dawson*: Professor Dawson is Chief Science Officer for Autism Speaks (NY, USA) where she oversees US$25–30 million in annual autism research funding. She is Research Professor of Psychiatry at the University of North Carolina at Chapel Hill (NC, USA), Adjunct Professor of Psychiatry at Columbia University (NY, USA) and Professor Emeritus of Psychology at the University of Washington (WA, USA). Dawson is a licensed clinical psychologist and researcher, and has published over 200 scientific articles and nine books related to autism, with a focus on early detection and intervention, brain development and plasticity. She developed and empirically validated the Early Start Denver Model, the first comprehensive intervention for toddlers with autism with Sally Rogers. From 1996 to 2008, Dawson was Founding Director of the University of Washington Autism Center where she directed three consecutive NIH Autism Center of Excellence research programs on genetics, neuroimaging, early diagnosis and treatment. She also oversaw a multidisciplinary autism treatment center serving children from infancy through to young adulthood. Dawson has been a consultant to the NIH since 1989 and currently serves as a member of the Interagency Autism Coordinating Committee. She is a Fellow of the Association for Psychological Science, American Psychological Association, and Society of Clinical Child and Adolescent Psychology, and is on the editorial boards of four scientific journals. She has received numerous awards for her work, including a James McKeen Cattell Lifetime Achievement Award from the Association for Psychological Science, the Geoffrey Beene Rock Star of Science Award, and Autism Society Awards for Valuable Service, Research Contributions and Medical Professional of the Year. Dawson’s scientific studies were recognized by the NIH as one of the top scientific advances in autism research in 2007, 2008, 2009 and 2010, and her research on the effects of early intervention on brain activity of children with autism was recognized by TIME Magazine (NY, USA) as one of the top ten medical breakthroughs of 2012. Dawson received a PhD in developmental and child clinical psychology from the University of California Los Angeles Neuropsychiatric Institute (CA, USA).

What originally drew you to the field of autism?
I made the decision to devote my career to autism when I was a graduate student. When I began training to be a clinical psychologist, my first case was a child with autism. At that time, autism was very rare; in fact, it was so unusual that they flew Eric Schopler (who was then a world expert in autism) to the University of Washington.

“...I knew that to understand autism we had to study children at a very young age, because, again, I was interested in the origin of the symptoms and when they emerged.”
(WA, USA) where I was training, and the child was presented at grand rounds. This boy then became one of my patients.

I was captivated in two ways. The first was from a scientific point of view. At that time, we had little understanding of the neural basis of social behavior. I was really interested in understanding how it was that a child could come into the world and not have the ability to form social relationships. I thought that if we understood that, we would understand something very fundamental about ourselves and how our brains work. Second, it captured my heart in the sense that I felt a lot of compassion for this little boy and, in particular, his family, and at that point we had very little to offer in terms of treatment. I decided then and there that I would devote my career to understanding autism and hopefully doing something that could make children’s and their families’ lives better.

Q How did your career develop from that point?

I decided then that I wanted to write my PhD thesis on autism. I was very interested in the brain basis of behavior, so I designed a study that would help us to understand why children with autism have trouble with language and with the ability to imitate others, and why they do so well in other areas, such as their ability to perceive visual patterns.

Therefore, my dissertation was very much focused on that topic. My training early on was interdisciplinary; in my clinical training I was part of a multi-disciplinary team that would evaluate a child from many different perspectives: language specialists, motor specialists, psychologists, pediatricians and neurologists. I had adopted an interdisciplinary perspective on science, and my perspective on autism and my dissertation were very much designed from that point of view. It involved electrophysiological measures taken while children were using language, imitating or completing visual motor tasks. My hypothesis was that dysfunction of the left temporal lobe was disrupting the ability to imitate and use language, and that imitation was the core deficit in autism. I also carried out computed axial tomography scans, neuropsychological testing and behavioral testing. I tried to integrate these areas in my original thesis, back in 1979.

At that point I thought that I would have a career in which I would be a specialist in a very rare condition. I never imagined that, 30 years later, autism would be one of the most common childhood conditions, nor did I imagine how much we would understand about autism, and some of the new breakthroughs in terms of treatment.

Q What do you feel have been your most significant achievements & contributions to the field of autism?

My contributions have been in three areas. The first is that in the 1980s it was believed that autism could not be diagnosed before the age of three. This was because the theoretical models of autism at that point were very much focused on mental abilities such as theory of mind, representation and language that emerged in the second and third years of life. However, I trained as a developmental psychologist, and my own observations of children in clinical practice suggested that the impairments were much more fundamental. In particular, I was intrigued by my clinical observation that when I entered the examination room, children with autism did not turn their heads and notice me. In this situation a typical child (even a shy child) would at least peak at you; they would be interested.

Children with autism do not have this basic orienting response. My colleagues and I later coined the term ‘social orienting’ in a 1998 paper to describe this behavior [1]. Therefore, with my understanding of infant development (early on in my career I did actually study infants), I was very interested in these more fundamental problems: social orienting and social attention. I posited that if these were part of autism, then you surely should be able to detect them in infants younger than 1 year old, or at least by 1 year of age. Therefore, in 1994, by observing home videotapes, Julie Osterling and I demonstrated that you could detect symptoms of autism in infants who later developed autism (our first study was with 1 year olds, and then we went on to show that you could observe symptoms at 8–10 months of age) [2,3]. This really
changed our perspective on autism – how it developed and how early we could recognize it. It also opened the door to the study of autism in infants.

The second area in which I made a contribution had to do with how you study early brain development in very young nonverbal children with autism, and some of the findings around early brain development in autism. I knew that to understand autism we had to study children at a very young age, because, again, I was interested in the origin of the symptoms and when they emerged. Our laboratory pioneered the use of event-related potentials and other electrophysiological techniques to study very early brain development in toddlers and preschool-age children with autism. Through that work we shed light on, for example, problems of face recognition [4]. We demonstrated that (in individuals with autism) fundamental parts of social brain circuitry are disrupted very early, and that autism involves these brain systems that emerge very early on in infancy. Our first study using electrophysiology with young children, published in 2002, showed that preschool-aged children with autism fail to exhibit a differential brain response (event-related brain potential) to their mother’s versus a stranger’s face, but did show a different response to a familiar versus unfamiliar object [5]. We later demonstrated this in toddlers and even adults with autism [6]. In 2004, Jamie McPartland, Sara Webb, Leslie Carver and I published the first study demonstrating that adolescents and young adults with autism fail to exhibit normal N170 responses to faces [7]. The N170 is a face-sensitive event-related potential response. To account for these findings, we proposed the ‘social motivation hypothesis’, which posited that the failure of children with autism to direct their attention to the social world stems from a lack of sensitivity to the reward value of social stimuli (described in [8]).

Third, in collaboration with Sally Rogers, I helped develop the first empirically validated early intensive behavioral intervention that is appropriate for infants as young as 12 months of age (the Early Start Denver Model; ESDM) [9]. This work is an extension of earlier work by Sally Rogers on intervention with preschool age children with autism [10]. In the ESDM, applied behavior analysis is integrated with a developmental, relationship-based approach. This was a new concept for the field because many viewed applied behavior analysis and developmental approaches as incompatible.

Q. Can you tell us more about the ESDM?

Sally and I both felt that the traditional applied behavioral analysis model was not consistent with what the science of developmental psychology and infant learning had taught us in the previous decade. Therefore, extending Sally Rogers’ earlier work, the ESDM brings in the concepts of early development that we understood from developmental psychology, such as the idea that learning occurs in the context of a social exchange, and that without that social foundational relationship it is very hard to teach things such as facial expressions and gestures, language and even cognitive skills. We wanted to incorporate intervention strategies that addressed the core deficit in social motivation. The model promoted social engagement by making social interactions rewarding for the child. The science of early learning had also taught us that infants and children are active learners, hypothesis testers who learn by experimenting on the world. We wanted to create an intervention that promotes this active learning style that typical infants and toddlers naturally engage in.

Since our 2010 paper demonstrating the efficacy of the ESDM [11], there has been a great interest in this approach. Our book describing the ESDM has been translated into ten languages, so there is broad interest in the model [9]. Last year we published a paper that showed that children who received early intensive behavioral intervention for 2 years using this model showed brain responses to social stimuli that were essentially indistinguishable from typical children, but very different from children who had not received the intervention [12]. That is to say, some of the early differences in brain activity that my colleagues and I had shown in previous work were associated with autism, such as a failure to have a normal brain response to
faces, were altered and normalized through early intervention.

Throughout my career I have written, along with several others, that autism is a condition that involves a very dynamic brain process that develops in interaction with the world. Many symptoms we associate with autism are probably a secondary consequence of being a child who, from infancy, is not paying attention to people or finding the social environment rewarding; if one can intervene and provide stimulation early on, then one can alter both the trajectory of brain development and the behavioral outcome.

That kind of neural plasticity is a concept that I wrote about early on [13], along with others, so I was really delighted to publish that particular finding showing normalization of brain activity as a result of early intervention. We felt very honored last year when *TIME Magazine* (NY, USA) recognized our study as one of the top ten medical breakthroughs of 2012. We were especially happy that people are recognizing the importance of early intervention in autism, and the general public, I think, is really encouraged by these kinds of findings. This study can hopefully help in our advocacy efforts to increase access to early intervention for children with autism.

**Q** While carrying out your research, have there been specific cases or individuals who have particularly inspired you?

Absolutely. I really enjoy spending time with people with autism. From a very early point in my career, I thought it was important to spend a lot of time with people of all ages with autism and to understand their perspective and development.

I have known and watched the development of many of the children that I diagnosed at the age of two all the way into adulthood. Along that path I have met so many people with autism and their families who have inspired me; it can be hard being a person with autism in our society, and they work really hard to succeed and be accepted by others. I have always found people with autism to be very inspirational in terms of their character and determination. I am also amazed by some of the talents that people with autism have in many different domains, their sense of humor and perspectives on life. I just have a great appreciation for people with autism and the unique perspective they bring into the world. There are many people who have touched me in that way.

**Q** You are currently Chief Science Officer for the organization Autism Speaks (NY, USA). Could you describe the aims of the organization?

The organization has four main pillars to its mission. The first is raising awareness about autism, and thus we put a lot of resources into our awareness campaign, which aims to help the general public to understand autism and parents to recognize autism so that treatment can start as early as possible.

The second is advocacy, and we are very much involved in legislative and other kinds of advocacy efforts. An important effort for Autism Speaks is insurance reform that aims to increase access to behavioral health services that are often not covered by insurance.

The third component is directly helping families by providing tool kits and many other online resources that can have immediate benefit to families, such as the ‘100 Day Kit’ (Autism Speaks) that helps parents navigate the first 100 days after their child receives a diagnosis of autism spectrum disorder.

Fourth is the science mission. We fund research that will discover the causes of autism and accelerate the development of more effective ways of diagnosing and treating autism with the aim of improving the lives of people with autism and their families.

**Q** What does your role entail?

I oversee the science program, which is the largest (in terms of resources) part of the overall mission for Autism Speaks. The annual science budget is between US$25 and 30 million per year, and approximately half of that money is spent on investigator-initiated awards. These are awards that are given to people who come to us with good ideas, which we evaluate based on scientific merit and alignment with our...
priorities. We also help to nurture new scientists with our pre- and post-doctoral fellowships, as well as funding high-risk, high-impact innovative research through our Trailblazer Awards. We fund a very diverse portfolio of research, from basic research into the causes of autism and the underlying basic biology, all the way to developing new treatments and new methods of disseminating these treatments to the community.

The other half of the funding is focused on targeted projects and resources for the scientific community. We provide certain kinds of resources to the scientific community that we think are important for accelerating discovery, such as providing ready access to a DNA database (the Autism Genetic Resource Exchange) and brain tissue (the Autism Tissue Program). We help people to collaborate through networks, meetings, conferences or workshops. Our targeted projects focus on areas we think are timely for investment. These targeted research projects often seek to fill critical gaps in knowledge, such as the development of effective treatments and services for adults with autism spectrum disorder.

Q Where is your organization’s research currently focused?
First of all, we have a strong focus on understanding the causes of autism, including both genetic and environmental risk factors. Second, we are funding research into understanding the basic biology of autism – animal models, brain imaging studies and other types of studies that are aimed at understanding, even on a molecular basis, what is disrupted in autism, with the goal of being able to restore or help remediate those impairments or disruptions.

The third focus is the area of treatment, and here we are investing in two main areas. The first is in the area of behavioral interventions, with a focus on very early intervention. For example, Autism Speaks funded the first randomized controlled trials of early intervention for infants and toddlers with autism. We also fund research on behavioral interventions throughout the lifespan, such as school-age social skills training, and adult behavioral interventions that can improve quality of life.

We are also investing in studies on biomedical interventions, and there are two areas we are emphasizing here. One area pertains to recognizing and treating medical comorbidities associated with autism. This funding supports the Autism Speaks Autism Treatment Network, a collaboration among 17 academic medical centers in the USA and Canada, in which we invest approximately $4 million a year. The network is addressing issues such as sleep and gastrointestinal problems, epilepsy, metabolic conditions, feeding disorders, nutrition, and psychiatric comorbidities such as anxiety and depression. By addressing these comorbidities, we can greatly improve the quality of life for individuals with autism. Another part of the effort of the Autism Speaks Autism Treatment Network is in creating toolkits and physician guidelines for the assessment and treatment of these comorbidities. For example, last fall, the Autism Speaks Autism Treatment Network, with support from the US federal government, published (in the journal Pediatrics) the first empirically based physician guidelines for the assessment and treatment of sleep disorders, gastrointestinal problems and ADHD in children with autism [14], and we have a number of other toolkits and guidelines that we will be rolling out later this year.

Another area that we have a strong focus on is the development of medicines that can address the core symptoms of autism. One of the most exciting breakthroughs in the last several years is that we are learning much more about the molecular basis of autism and what pathways in the brain are affected. These insights are coming from many of years of investment in genetics and, more recently, research on genetic animal models of autism. We are learning that autism spectrum disorders involve disruptions of synaptic functioning, which is the basis of learning and memory. Signaling pathways, such as the mGluR5 pathway, are being identified as potential targets for pharmacological intervention in autism. The
pharmaceutical and research communities are currently testing medicines that could potentially help restore the functioning of these pathways in the brain, with the goal of reversing or reducing some of the core symptoms of autism, such as difficulties involving social interaction, learning and communication. This work largely depends on genetic animal models that are fundamental to understanding these pathways. Autism Speaks has been investing in standardizing and expanding the types of animal models for validating drug targets. We are also helping to fund clinical trials that are testing some of these new compounds.

Most recently, we realized that in order to develop new drugs that could address core and associated symptoms, we need to partner with the pharmaceutical industry, because academia does not make drugs, and Autism Speaks certainly does not make drugs. The pharmaceutical companies are responsible for bringing drugs to market, and they have a tremendous amount of resources, both scientific and financial, that are important for accelerating this area of discovery. This year we formed an affiliate organization to Autism Speaks called Delivering Scientific Innovation for Autism, which is a nonprofit organization that is partnering with the pharmaceutical companies and other for-profit companies on projects that are discovering, testing and bringing new products to market. These products are not only medicines, but also technologies, diagnostics and services.

Finally, as we develop and validate new ways of diagnosing and treating autism, it is very important that we do not stop there, because our goal is not simply to generate knowledge that will sit on the shelf. We have to make sure that findings are disseminated and implemented widely in the community. For example, we know how to diagnose autism at 18–24 months of age, and yet the average age of diagnosis for a child with autism in the USA is 5 years of age, and for children from an ethnic minority background or with Asperger’s syndrome it is even older. Autism Speaks has set a goal of reducing the age of diagnosis of autism and increasing access to interventions.

Clearly, if we want to improve the lives of people with autism, we have to focus on the dissemination of knowledge; through the Autism Speaks Global Autism Public Health Initiative, we are working within the USA and collaborating with over 40 countries worldwide. Some of these regions have very little resources, such as India and Africa. In some cases, they are higher-resource countries, such as Albania, that are seeking necessary professional training. In all cases, the goal is to promote collaboration and increase capacity for research, services and training.

Q: How do you see the future of autism research?

I believe that there are several important areas in which we are going to continue to see remarkable progress. I think that over the next 5 years or so we are going to discover diagnostic biomarkers and means of very early detection of autism, offering the possibility of providing interventions before the full syndrome is manifest. We may even see the prevention or at least the amelioration of the disabling aspects of autism.

Another area is drug discovery for addressing the core autism symptoms. If we can – and I do think we are more hopeful than ever – develop medicines that can begin to restore some of the pathways in the brain that are affected in autism, and if this could help in alleviating problems in social interaction, learning and language, this would be revolutionary in terms of the way we think about treating autism or even the way we think about autism as a disorder. I think one of the most exciting ideas that comes from recent animal model studies is that these treatments may not necessarily have to be given early in development to be effective; even in adulthood they potentially could have benefits. Since autism is not one condition, but a set of different conditions that affect certain shared brain pathways, the discovery of biomarkers based on, for example, genes or gene expression, as well as other types of biomarkers, will be critical in helping identify which people with autism will be helped best by which treatments. This will help us deal with the problem of heterogeneity, which has been a vexing challenge in autism.
Adult development is another important area of research. We have focused so much on children and we have well-validated behavioral interventions for young children, and are beginning to see more and more studies as we move into elementary school and adolescent ages. When you move into the area of adulthood, however, we have very little knowledge of the health risks, the best ways to provide behavioral and medical support, or even what aging looks like in autism. I think we will begin to appreciate more fully that people with autism live the majority of their lives as adults, and that we need to put much more into resources that will help adults live successful and fulfilling lives.

Finally, in terms of understanding the causes of autism, we continue to make great strides in understanding both environmental and genetic risk factors, and I think that this is going to end up having very significant implications for efforts focused on prevention of disability associated with autism as well as early diagnosis.

**Financial & competing interests disclosure**

G Dawson is co-author with S Rogers of Early Start Denver Model for Young Children with Autism and An Early Start for Your Child with Autism, from which G Dawson receives royalties. G Dawson has no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

No writing assistance was utilized in the production of this manuscript.

**References**


