

VIEWPOINT

Catherine Lord: Lessons from a storied career in autism research

BY CATHERINE LORD

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I have studied autism for almost 50 years now. My focus on the condition was not planned. Rather, it was a product of being in the presence of extraordinary researchers, clinicians and trainees who challenged me to keep evolving as our understanding of autism evolved.

The most important factor in my success has probably been the long-term clinical relationships I have had with families and children, many of whom are now adults. This, more than anything else, afforded me opportunities to think creatively and try innovative approaches.

I have worked on a range of behavioral therapies for autism, from **applied behavior analysis** to psychodynamics to the **TEACCH** approach to structured learning. I worked with families using a variety of low-intensity treatments as a preschool special-education teacher, and then with consultations and long-term follow-ups as a clinician — over decades in some cases.

Over the course of my career, I have become unapologetically eclectic in the therapies I select, tailoring these to the individual and situation.

I have tried to keep a similarly open mind about diagnostic tools, because they can sometimes prove useful well outside of their intended purpose. I developed the Autism Diagnostic Observation Schedule (ADOS) with **Sir Michael Rutter** and other colleagues in the 1980s in part to find and document ‘pure’ autism — an aim we now recognize as naive. In creating it, we inadvertently helped the field move beyond relying on subjective ‘clinical diagnoses,’ without standard expectations for the data needed to make these decisions.

These days, I believe the ADOS’ greatest value is in helping clinicians and families understand current conceptualizations of autism and discuss how each individual child fits — or does not fit — into these constructs, particularly over time. Yet in many clinics, this aspect of the ADOS is overlooked. And in schools, caregivers are not always invited to observe the test.

Some experts criticize the ADOS, arguing either that it is too subjective or, ironically, that it discounts their subjective clinical knowledge. They also argue that it adds extra costs, which is true. What is the alternative? We cannot return to the days of non-standardized assessments or to the elitism of the 1980s, when autism research was monopolized by well-known physicians from elite institutions.

Clinical advantage:

Over the past 20 years, powerful people have told me time and again that I should stick to government-funded research because that is where I can make the biggest impact; that seeing families and working with other groups wastes precious time. This attitude has shifted. Perhaps that is because I am older. Or perhaps it is because medical schools increasingly depend on philanthropy and clinical revenue to survive.

Meanwhile, top clinical-psychology graduate programs have shifted their focus to neurobiological mechanisms and big data — and increasingly exclude autism from the syllabus. Unlike medical schools, these programs do not rely on clinical revenue, and their leaders can focus entirely on accumulating prestige and grants, which seems a shame for autism research.

It behooves us to train a new generation to do what we do. The benefit runs both ways — we learn from our trainees as we watch them learn. After being mentored by a string of ‘Great Men,’ I have been especially keen to mentor female scientists.

When I started out as a researcher, I was often one of few women in a department. At one point, I was one of only two female professors in a medical school. This has changed somewhat; clinical psychology and psychiatry are now primarily female professions, but the ranks of the most powerful researchers remain male.

Gender aside, I am acutely aware of my advantage as a clinical psychologist trained in the United States. Here, following intensive scholarly training that typically involves concurrent clinical work and research, we work as independent investigators and clinicians alongside medical professionals. Other countries have research led by psychologists, but often with less recognition of clinical psychology training in research.

I feel fortunate to have trained where I did, and to have worked with the scientists and families that I have. Interactions with them have made me a better clinician and a better researcher.

Life lessons:

I cannot overemphasize the element of good luck in my career, but a handful of tenets have surely

helped me on my way:

Take advantage of learning opportunities, wherever they appear.

I went to Harvard University intending to explore how children think. Changes in faculty caused me to veer into infant perception and then into psycholinguistics, both of which contribute to my work in autism today. As a clinician, the most important thing I learned from embracing new therapies was the value of respecting families and schools.

Prioritize your time.

You will never have enough of it; be shrewd in how you allocate it. For me, this means balancing clinical work with children, adults and families; mentoring students; and conducting research that doesn't just sound clever but might actually make a difference.

Be honest, be humble and set high standards for your work.

It is easy to exaggerate the potential effects of a study and to reify what you have done: Don't. Other people will do this for you if the work is solid.

Avoid making ad hominem comments about others' research.

We do not need to tear one another down. By all means, state your desire for the field to do better, but do not overstate your own capacity to solve complicated problems. And try not to criticize others just to boost your own contribution.

Keep good people close.

I was lucky; several of my mentors placed equal importance on research and high-quality clinical work. This is not a given in academic medicine or at universities. My advice: Pick your bosses carefully. Similarly, students, postdoctoral researchers and colleagues enrich your work by asking questions you had not thought of and offering fresh perspectives. Hold onto them as friends and collaborators — you will be grateful that you know them.

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