Because of Alex—Notes on Trailblazers

by Clarence E. Schutt, Ph.D.

Last weekend, Alex, my 14 year old son with autism, resumed a project of building his own swimming pool in our back yard. He had begun last summer by directing a jet of water from the garden hose into an ever-expanding mudhole. Every so often, he would step into the ankle deep muddy water to check his progress. After several days, he had a breakthrough. He discovered that by planting our pet dog’s stainless steel water dish in the middle of the mudhole he could create a clear water pool. He quickly realized that his eighteen inch “pool” didn’t measure up to his expectations and redirected his attention to jumping into the small (6 foot) plastic pool he normally uses.

As I watched him stepping into his self-made pool, my memory took me back more than ten years to when I first established serious eye contact with Alex. I had been trying to catch his attention at the edge of the pool at our swim club by waving my arms and trying to get him to jump to me and, for just a fleeting moment, he looked into my eyes and jumped. That was just the beginning. Later that summer, we progressed to the point of diving to meet open-eyed under water, where we would begin to laugh and hug as we rose to the surface. Parents of “normal” toddlers asked me what my secret was in teaching him to dive with such confidence. I never knew where to begin.

My NAAR-related work often takes me to New York City to meet with potential donors or to attend meetings. A one-car train, affectionately known as “The Dinky”, shuttles passengers between the Princeton University campus and the main line running along the Eastern Seaboard. It is not unusual to recognize someone at the station, a former student or fellow faculty member. A brief nod of recognition or exchange of pleasantries is enough to maintain our distance as we seek out separate seats on the train. I like to use the hour-long trip into the City to read recent issues of Nature or Science. Often some article sets me to musing about cures and treatments for autism - Alex is never far from my mind. Indeed, in the past few months I’ve spent the time on the train reading about sensational discoveries reported by some of my Princeton colleagues.

Once I get off the train at Penn Station in New York and begin to make my way through the crowd, it is rare that I spot anyone I know from among the hundreds of persons I pass. It is a curious and generally unremarked fact of human nature that in the instant it takes to scan a face we immediately realize that we don’t know someone. Some researchers believe, based on recent brain imaging data, that individuals with autism find it difficult to perform this everyday act of magic and avert their gazes to avoid trying. Maybe so.

Occasionally in one of New York’s many museums or galleries, or along Park Avenue, a “celebrity face” will jump out and a little shot of adrenaline surges through my body. Recently, near Broadway, I unexpectedly ran into two well-known Californian advocates for services for adults with autism. Their faces were instantly recognizable, even though we see each other only once per year and I had no reason to suspect that they would be in New York. No brief exchange of pleasantries on that occasion!

Professor Charles Gross, a distinguished colleague of mine in the Psychology Department, has spent many years studying the mechanisms in the brain responsible for face recognition and for perceiving one’s place in space. He recently published an article in Science demonstrating that neurons in the hippocampus, the region of the brain required for associating immediate sensory information with long-term memory, can be replenished, contradicting the long-held view that brain cells do not divide. This pioneering discovery offers hope that damaged brains might be repaired by stimulating natural restorative processes by the application of growth factors or pharmaceuticals. The hippocampus has sometimes been called “the gateway to the mind”.

Several lines of research suggest that the hippocampus in individuals with autism may not be functioning properly, perhaps because the number of neurons is reduced, or available neurons are not able to sprout “mossy fibers” of high enough density for high speed processing of complex inputs (like faces or sentences). But, I’ve never had much worry about Alex’s spatial memory or ability to plan.

One winter’s day, when he couldn’t have been more than six years old, he took my hand and headed out across nearby Springdale Golf Course, through the Einstein Woods, all the way to the chained gates of our summer swimming club, a half mile away, where he had first learned to swim. It amazed me that he charted a course quite different from the route traveled in the reliable old 1953 Buick Special that usually carried us down the short dusty road to the pool. I should have anticipated that Alex wouldn’t understand the chains and locks at the gate keeping him from the water on this cold
winter’s day and the image of him violently shaking at the gates haunts me still.

Scientists are beginning to understand at the biochemical level how the connections between cognition and emotion are mediated by hormones, and surely this knowledge will help our children. Charlie Gross co-authored the Science paper on neuron rebirth mentioned above with another Princeton colleague, Professor Elizabeth Gould, a rising star in the neuroscience firmament. Liz was one of the first scientists to demonstrate that neurons in the hippocampus respond to steroid hormones by increasing or decreasing the number of potential sites on their surfaces that can synapse (“join with”) other neurons in the “nets” of neurons that capture and refine our thoughts and memories.

This important discovery reveals one of the ways in which our brains respond to stressful situations and how emotional states may affect learning. Conceiving or fixing a plan in our minds seems to require hormonal stimulus to maintain or strengthen active memory and learning circuits. We all learn better when we’re excited. There is an excellent book by Antonio Damasio on the “mind-body” problem (The Feeling of What Happens) in which he argues that “consciousness” itself, the sense we have that we are here, may be just another emotion.

On that cold day at the gate, Alex just couldn’t adjust to the fact that his plan had been thwarted. It must have been hard for him to drop it, not that he didn’t understand, but because his powerful determination was sustained by strong neural-hormonal circuits that he couldn’t control. I sometimes wonder if sometime ten thousand years ago, when the human population dwindled to a dangerously small number, whether some autistic person led our species to safety, or to a fresh water supply, because they had the determination and clear-headedness to blaze a new trail.

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Editor’s Note: Thoughts on Karin Nelson’s Preliminary Findings

by Catherine Johnson, Ph.D.

Dr. Nelson’s study raises interesting questions concerning early versus late onset autism. It would be interesting to know whether there were “regressive” children in her study, and if so how many.

Assuming she did have late onset children in her sample (you’d expect 20 or so in a group of 65) it would be interesting to know whether their levels of these brain proteins, though apparently higher than those in typical newborns, differed in any way from those in the early onset kids. If not, if the early onset and late onset children showed roughly the same elevated levels, this might tell us that the relationship between late and early onset autism may be different than what many had believed.

For a number of years, of course, clinicians assumed that parents of late onset children simply missed the signs that their children were different. But that view may be changing. A recent “Brief Report” from the University of Washington, published in the Journal of Autism and Developmental Disorders, found that researchers could retrospectively identify “autistic” 8 to 10 month olds with a high degree of accuracy from home videotapes—but only when they removed late onset children from the analysis.

The question of regressive versus nonregressive children has gained more attention of late not only due to the controversy over vaccines, but also with increasing knowledge of Landau Kleffner Syndrome, or LKS, a regressive epileptic disorder similar to autism in many ways. Work on LKS has led many researchers to believe that regression in early onset children is more widespread than clinicians realize. Roberto Tuchman, a member of NAAR’s Scientific Advisory Board and a pediatric neurologist who is an authority on LKS as well as on epilepsy in autism, observes that many nonregressive children do show regression in “communicative intent.” An early onset child who was talking at 12 months will continue to talk—he won’t lose his words as regressive children do—but he may stop seeming to want to talk. He does not lose skills, he loses intent to use his skills.

Is it possible that a similar genetic and/or environmental event “tips” all children with autism either from normal to autistic (in the case of regressive autism), or from “slightly” autistic to “severely” or “full-blown” autistic, as parents of nonregressive children often report when describing the developmental history of their children?

In a future issue of NAARRATIVE we hope to examine the issue of regressive versus nonregressive autism, and to bring you Dr. Tuchman’s discoveries and clinical approach to treating language in children with severe language loss.

On another subject, it would also be interesting to know what the levels of these chemicals are in babies with Asperger’s syndrome. Even more intriguing, what might the levels of these proteins look like in children like Temple Grandin who begin life with classic autism but progress to high-functioning autism?

We all, parents, teachers and researchers alike, have a great deal to think about. At least we will have a great deal to think about if Dr. Nelson’s findings are confirmed. And we hope that we learn the validity of her results soon, one way or the other.

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