An Interview with Ari Ne’eman, President of Autism Self Advocacy Network

Asperger’s: A Disability, And A Gift

Ha Gets Last Laugh On ‘Master Chef’

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Medicaid Advocates We Need You

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Medicaid Advocates: We Need You
By Janine Bertram Kemp

It’s time to get involved.

At press time for this issue of Independence Today, governors in all but 14 states have indicated support for Medicaid expansion. A recent Rand Corp. study indicated that states that refuse to expand Medicaid will lose out on more than $8 billion and leave millions of citizens in poverty.

In some states, centers for independent living (CILs) are part of broad-based coalitions, such as Texas’ My Medicaid Matters, that are negotiating what long-term services and supports (LTSS) will look like under their state Medicaid plans.

Under Center for Medicare and Medicaid Services (CMS) guidelines, LTSS includes both institutional-based services and home- and community-based services (HCBS). The CMS guidelines encourage states to include both HCBS and institutional programs in the managed-care capitation rate (the fixed amount CMS pays to a managed-care plan selected by an enrolled Medicare beneficiary).

For advocates who want people out of institutions and in the community, that means you must make sure that both institutional programs and HCBS are the responsibility of the managed care organization (MCO) and that the institutional programs are not “carved out.”

“Our assumption is, if a managed care agency is financially responsible for institutional-based services, the MCO will figure out how to serve the person in the community, where on average it’s less expensive,” says Americans with Disabilities Act attorney Steve Gold. “If the MCO is not responsible for institutional services, the MCO will have a financial incentive to dump people with disabilities -- especially with severe disabilities -- into the institution.”

“Managed care seems to be an inevitability as the Congress debates entitlement ‘reform’ and states try to make sense out of their growing Medicaid programs. We can bitch and moan, or we can make managed care work for us,” says Bob Kafka, National ADAPT organizer. “It’s important that we are at the negotiating table so we can shape state policies and contracts that will result in a system that has a functionally based eligibility system, is person centered, and (is) consumer directed with people with disabilities living in their own...
Autism Group Founder: It's Time to Listen to What We Have to Say

By Mike Ervin

Ari Ne’eman is one of the wisest, most eloquent young leaders in the disability rights movement. As president of the Autism Self Advocacy Network (ASAN), he insists that people with autism speak for themselves and determine their own service and advocacy priorities. This has often put him at sharp odds with more traditional service providers and advocacy organizations such as Autism Speaks, which he says “talk about us without us.”

Ne’eman founded ASAN in 2006 when he was a 19-year-old freshman at the University of Maryland, Baltimore County. In 2007, ASAN got its first big chance to mobilize when the New York University Child Study Center launched a so-called “public service campaign” regarding childhood psychiatric conditions such as autism. The campaign consisted of several “ransom notes” posters displayed in such places as New York City billboards and published in periodicals such as Newsweek. The ads depicted autism as a vicious, sadistic kidnapper holding helpless autistic children hostage. Like the Jerry Lewis Muscular Dystrophy Association Telethon and other paternalistic publicity campaigns that have stirred the ire of disabled activists, ransom notes implied that living with a disability is tragic and hopeless and the only solution is a cure.

A relentless, two-year, Internet-generated charge led by ASAN pressured the Child Study Center to grudgingly shut down the campaign after a barrage of angry emails and bad publicity. ASAN established itself as a significant new force in the disability rights movement

Ne’eman, who grew up in East Brunswick Township, N.J., doesn’t discuss his childhood disability experience in much detail. “My experience growing up was similar to that of most autistic people,” he said. “We struggle socially. I had very strong interests in particular topics.”

He was diagnosed with Asperger syndrome at age 12 in 2000 and was shipped off to a segregated school. “Instead of walking to my local high school, I took a van about an hour and a half north,” he said. “After the first few weeks I was there, I started wanting to get out. One day I left in the middle of the school day, and I got picked up and brought back pretty quick.”

Ne’eman self-advocated his way out of the school after two years, and he graduated from his neighborhood school, East Brunswick High School. He went on to earn a bachelor’s degree in political science.

Ne’eman is one of four full-time and two part-time employees of ASAN, which lists 15 U.S. chapters on its website. Ne’eman was appointed by President Obama to the National Council on Disability. Independence Today spoke with him recently about his thoughts and experiences.

Q: What was the atmosphere in the segregated school?

A: On the positive side, I started to connect with other autistic people and get this feeling of culture and community, and on the negative side, I saw how people were...
Two Memoirs Give Honest Look at Personal Disability Experience
By Deborah Kendrick

For years, my already excessive reading life has included scores of memoirs and autobiographies written by individuals with various disabilities.

Like any genre, the outcome of such efforts is mixed. Some present a set of life’s experiences with an “aw, shucks; it was nothing” kind of dance I find cloying at best. Others inflate mediocore accomplishments as inspirational simply because a disability was part of the experience. Every once in a while, this quest unearths a book that is compelling, candid and yes, inspirational, while managing to provide a genuine picture of disability as it is blended into the fabric of life.

Two such treasures are those written by actor Michael J. Fox and law professor Elyn R. Saks. Each takes us on an up-close and personal tour of a gripping disability experience, and each does so with brilliance, humor and a clear admission of struggle with an equally clear absence of self-pity.

Whether you first knew him as Alex P. Keaton in the 1980s TV series “Family Ties” or as Marty McFly in the movie trilogy “Back to the Future,” you knew Michael J. Fox as a hilarious, always youthful, charismatic actor. In this first of three memoirs, Fox maintains that light-heart-ed, ironic appreciation of the absurd with an honest willingness to laugh at everything, including himself.

In “Lucky Man: A Memoir” (Hyperion, 2002), Fox vividly recaptures the morning in 1990 when he woke up in a Florida hotel, hung over from alcohol and mystified by the “message” in his left hand. The “message” was the first uncontrollable twitching that was eventually diagnosed as early onset Parkinson’s, a condition he would keep secret for nearly a decade.

Fox was born in 1961 to a Canadian military family. He reminisces about his childhood with warmth and laughter, replete with anecdotes clearly indicating his future in entertainment. At 18, he headed off to Hollywood, the proverbial quest to find stardom.

He adds that this system must have attendants that are paid a livable wage with benefits. Frequently, the people who do attendant work, whether in a consumer-directed or agency delivery system, are forgotten.

With refreshing, albeit sometimes painful, candor, he describes how quickly he became a spoiled, self-absorbed and alcoholic celebrity. We see the complexity of the young Fox, someone who adored his grandmother and other family members, was astonished by his own success, and readily admits that he was not prepared to handle it.

Kafka says that many states have a variety of Medicaid state plan and HCBS waiver programs that are administratively expensive and are based on specific disability labels or age. It would be more effective, he says, to have a system with a unified budget, a single point of entry and functional assessments of each individual so people get a menu of services based on what they need rather than on what they are labeled.

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Hafner says that CILs still can provide key services as subcontractors under the MCO model.

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“We used to chant, ‘Label jars, not people!’ Now we have an opportunity to implement that slogan,” Kafka says. “Each person can be assessed and receive supports for what he or she needs to live in their own home and community. There would be considerable savings in not paying for the administration of myriad waiver programs.”

“In Maryland, CILs are talking amongst themselves about what role they want to play in Community First Choice,” she says. “Do they want to be the supports and planning broker, or is that a medical model style that advocates won’t touch? Can peer services be built in to the broker job description? Can CILs provide training in managing personal assistants? The smarter CILs are lining up to be part of the health care exchange network. They will be the navigators, fund-

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Back in the mid-1980s, when my freelance career had begun but publications were not available to me as they are today through the miracles of technology, I would sometimes spend afternoons with one particular friend, attacking a pile of magazines like beans to be snapped.

Emily was a wonderful blend of surrogate mom, friend, administrative assistant and translator. We would read the table of contents of a magazine, zip through certain articles – I would direct and she would read – getting snippets of content and style to get a feel for whether the magazine was a potential candidate for my work. And, of course, she would describe photos to me.

In one of those heart-wrenching moments frozen in memory, I recall her picking up one magazine of particular interest to me one day and commenting, “On the cover, there’s a picture of a Mongoloid child…”

I shuddered. The word was like an electric shock to my head and my heart, and I could barely speak. “We don’t use that word anymore,” I remember sort of mumbling, feeling awash with shame that this person so dear to me had uttered such ugliness. “I think you mean a child with Down syndrome.”

“Mongoloid” was, of course, the accepted language of her generation. She was not a bigot. She had worked for social justice in a variety of ways and counted among her friends people across an array of socioeconomic groups. But no one yet had told her that it was unkind or disrespectful to refer to a child who happened to have a certain genetic difference as a Mongoloid.

Even before there was such a widespread move to clean up our language with regard to disability, I had on many occasions experienced that familiar shudder, that visceral recoil when I heard certain words and phrases -- “crippled,” “spastic,” “retard,” “deaf and dumb,” “imbecile” -- that managed to dehumanize people with disabilities. We all know the degrading lexicon that has been used to label us over the centuries.

The word “blind” could fill an entire essay in its own right. Our casual references to “blind faith,” “blind love,” “turning a blind eye” and so on all employ the adjective to connote ignorance and cluelessness. But let’s talk about the words that we have actually managed to expunge, or nearly so, from our common vocabulary.

Although we still have “handicapped parking”

Eating -- whether finding comfort from mac and cheese or savoring seared scallops -- is one of life’s greatest pleasures. Few things are more captivating than watching a fabulous chef in action. Yet, though many who are blind have learned to cook as well as their sighted peers, it’s often believed that people with low vision can’t engage in the culinary arts. Christine Ha, the first blind contestant on the Fox TV show “Master Chef,” blew this misperception to bits.

Ha, who is legally blind, was the winner of “Master Chef” Season 3. She won $250,000 and a cookbook deal by defeating more than 30,000 home cooks across America for the “master chef” title. Her cookbook, “Recipes From My Own Kitchen” from Rodale Books, is now available in print and e-books.

Ha, 34, earned an M.F.A. (Master of Fine Arts) degree from the University of Houston’s creative writing program. With her husband, Ha hopes to open a gastropub in Houston, where they both live.

“It has been a dream of mine,” Ha wrote by email, “because that’s exactly the kind of spot my hus-
and then, in short order, returned to urging me to come to a gathering to chant.

Flash forward to a day or two after the shooting. I am in a two-person hospital room in Brooklyn’s Long Island College Hospital hooked up to several tubes and I am, not surprisingly, in rather poor shape. But my roommate is in worse shape than I am. He is an older man named John. He is in a coma and is being fed through a nasogastric tube.

I get a phone call from Susan. She’d gotten the number to my hospital room and a rundown of my situation from David, my apartment mate. She says she is in a subway station with two of her fellow chanters, and they are coming to the hospital to chant over me! On her end of the phone, I hear a train approaching in the background. To my dismay, the train drowns out my pleas (heartfelt, I assure you) that maybe, just maybe, they could come chant over me some other time. No such luck. She is off the phone.

The chanters are coming.

Now, I do not know all the specifics of what nurses are required to study in nursing school, but I think it is safe to say that helping a patient manage an impending invasion of chanters is not in any of the lesson plans. Luckily for me, the nurses taking care of me were, as I was about to find out, capable of managing anything.

I ring the call bell. I tell them of my problem: the impending invasion of chanters. In short order we (actually, they) devise a chanter’s management plan based on two concrete realities. First, we know John is in a coma. Second, the chanters don’t know John is in a coma.

When Susan, accompanied by her two fellow chanters, comes into the room that afternoon, the TV and lights are off, and I am lying in bed looking up at the ceiling.

Susan says: “Hi, Peter. How are you? We thought we – “

I raise my hand, gently cutting her off, and whisper:

“Look, I would love it if you could chant over me. But you see him?” I nod in the direction of John. The chanters nod that they see him. “Well, they just got him to sleep. Hasn’t slept in days ‘cause of pain. The poor guy’s been in pain for a long time. If we chant, we might wake him.”

The plan works. They leave. I thank John. A couple of nurses come in smiling. We have pulled it off. The next day I learned that the chanters had gone to the nursing station to double check that chanting would have been a bad idea at the time of their arrival because of Peter’s roommate. Oh yes, these wonderful nurses assured them, it would be a very bad idea.

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Henry Claypool, senior vice president at the American Association of Persons with Disabilities, began his career at the Center for People with Disabilities in Boulder, Colo. He first learned how to schedule personal care assistants, then managed a home health agency, and later directed the center. He has held positions at CMS and most recently as principal deputy administrator at the Administration on Community Living. Claypool, who lives with a spinal cord injury, is an expert in Medicaid and HCBS. When discussing advances made in Medicaid HCBS and LTSS under the Obama administration, many leading advocates credit Claypool.

“Advocates in the states should be advocating for expanding HCBS and state rebalancing programs,” Claypool says. “They should urge states to take up available incentives like Money Follows the Person, although 45 states now have MFP. States should apply for BIP, the Balancing Incentives Program. Advocates should also push states to apply for the Community First Choice option and HCBS state plan option 1915(l).”

ADA attorney Gold’s most recent information update on Medicaid noted five key points on the CMS-issued publication “Guidance to States using 1115 Demonstrations or 1915(b) Waivers for Managed Long Term Services and Supports Programs.” If your state is applying for a 1115 demonstration or 1915(b) waiver, you should review and follow Gold’s guidance. (Most states are applying because it means additional federal funds for state Medicaid programs).
People First language is more or less adopted in journalism now, so “that guy who uses a wheelchair” or “that girl with cerebral palsy” is becoming happily habitual. It is with deepest gratitude that I recognize it has been a long time since I’ve seen or heard “cripple” or “spastic” in any context.

We still, however, have miles to go. Even some of the new replacements are offensive to some of us. “Special needs,” for instance, has the proverbial nails-on-chalkboard effect on me. On one hand, it clearly denotes shame. Instead of calling a difference what it is, such as “my son has autism,” we say, “my son has special needs.” Translation: I am too embarrassed to name the set of traits that marks my child as “different,” so I’ll just pigeonhole him as “special needs.” On the other hand, it’s just plain dumb. Everyone has special needs! Isn’t my preference for dark chocolate over light special? Isn’t your love of folk music over jazz special? As a lover of clarity, I find “special needs” silly and vague.

Still, some words are so bluntly hurtful that legislators have weighed in. In 2010, an act of Congress mandated a change from “mental retardation” to “intellectual disability” in all references in federal laws and programs. In response to the ongoing campaign to eliminate the R-word, many states have now passed similar laws. Organizations and agencies across the country are changing their names.

Clearly, recognition is spreading that the word “retarded” is fraught with the connotation of incapacity or stupidity. And yet, we all hear in casual conversations a reference to someone who has done something foolish as being a “retard.” Legislation is helping, but it can only go so far.

Last year, two senators, Kent Conrad, D-N.D., and Mike Crapo, R-Ind., introduced a bill designed to put an end to yet another dehumanizing identifier. The legislation is dubbed the 21st Century Language Act of 2012, and its aim is to remove the word lunatic from the first section of U.S. code, a section of basic definitions.

The term “lunatic” has been around for centuries, originally connected to the notion that certain kinds of “madness” were induced by particular phases of the moon. The senators say that because even the psychiatric profession abandoned the term long ago, it just plain has no business appearing in U.S. code and should be re-
talking about autism and autistic people.

The first thing I noticed there was that when I was in public school, the emphasis was on teaching us academic topics. In the segregated school, the emphasis was on teaching us how they thought we should behave. There was this idea that by removing us from our local communities and schools and sitting us down and telling us how we were supposed to behave, we would be better off interacting with people and (would) succeed in life. We were no longer given the opportunity to get an academic education or to define our own goals.

I responded rather poorly to the often rigid expectations of the school environment. There was always this emphasis after I left the special ed school on trying to present me and the others who left as the “good” disabled kids: “You have potential. You have a future. You can be included. And the people who are still there -- they don’t fall into that category.” I still don’t buy into that message. I fundamentally don’t believe there is that much difference between me and my classmates that meant that I was deserving to do the things I wanted to with my life and they weren’t. That experience taught me how arbitrary the things that lead to a person with a disability being able to succeed or fail in life can often be.

There’s always this implicit bargain that you see in those educational environments where they say, “We’ll recognize your worth if you put yourself above the other disabled students.”

**Q:** Why do you think that bargain exists?

**A:** It’s about power. We’re in a period of tremendous change. If you go back 10 years in the autism world, the voices of self-advocates were nonexistent. Thanks in part to the work we’ve been doing, it is now an embarrassing thing to be excluding autistic people from conversations about autism. That doesn’t mean that the people who were in the business of excluding us are willing to give up the power they once had. They’re looking for people who are going to tell their stories but not put any meaningful demands on them. So it’s our responsibility as folks who are active in the disability rights movement and have some prominence to not be the easy self-advocates, to not just speak on our own behalf, but to link our experience to the larger experience of disabled people.

You see that come up in the political context disabled adults work in. Particularly in the developmental disability and psychiatric community, there is tremendous pressure coming from service providers, professionals and parents’ groups to let yourself be separated into that subset of disabled people that get deemed as capable. If you’re not willing to do that, you pretty much have no choice but to join the real disability rights movement.

The biggest thing I took out of my experience in a special education environment is understanding how fundamentally arbitrary and also how ridiculous and unjust those distinctions can be. This was a useful framework for me to have for the beginning of my advocacy.

**Q:** How did you discover the larger disability rights movement?

**A:** The Internet has been incredibly important for me. The first autistic people I connected with who had the same views and frustrations with the status quo were online. I learned about the existence of a larger disability rights movement online. That was very powerful.

**Q:** When you founded ASAN, what did you envision?
He pokes fun at the dissimilarities between himself and typical Hollywood celebrities – his youthful appearance, his short stature – and the same endearing qualities that drew so many of us to his earliest award-winning roles ring true on every page.

We learn about his battles with Parkinson’s: the details of agonizing physical changes, the almost Herculean (and sometimes comical) wrestling matches he has with his own limbs to keep them under control lest he give his condition away, and the quest for medical knowledge many readers with disabilities will find familiar.

He doesn’t ignore the stories that reveal his earlier self as an occasional jerk or the recognition of his problem with alcohol. But neither does he fail to express the love and gratitude he feels for his wife, his children, his family and his fans.

Another notable incident that undoubtedly will resonate with many readers is Fox’s decision to tell the world about his condition. After a decade of shame and the sometimes bizarre machinations he used to hide his disability, he ultimately shared his secret and then became a leading activist in raising awareness of and seeking a cure for Parkinson’s disease.

If you weren’t already a fan of this actor, author, producer, and activist from his many award-winning artistic endeavors, you will be after reading this book. It is written with warmth, irony and acceptance and the clear message that any disability can still take a back seat to a full and rewarding life.

Saks’ memoir, “The Center Cannot Hold: My Journey Through Madness” (Hyperion, 2008), reads like a fascinating novel, but it is so much more. With vivid detail and excruciating honesty, Saks brings the reader on a terrifying roller coaster ride of her own episodes with psychosis.

Not working.

Before my vision loss, I worked with software – doing accounting and consulting for oil and gas firms. It wasn’t satisfying. I felt like I wasn’t fulfilling my purpose on this earth. Losing vision was in a way a blessing in disguise. Life is too short not to do what you want – what you love.

I did some research and learned about rehab (vocational rehabilitation). I learned about adaptive tools to use in the kitchen. I adjusted slowly and began to live more independently. I went back to school to get my master’s in creative writing.

Q: How did the other contestants and the public react to your vision impairment when you were on “Master Chef?” Did they wonder how someone who’s blind could enter the fray?

A: I think everyone had that question. Because I was in the top 100 (contestants), some people thought having me on the show was a stunt – that I was on as a gimmick to increase ratings. They’d ask me, “Who’s going to use the knife for you?” I was like, “Me.” They didn’t take me seriously. I wasn’t hurt by that. I knew that if they didn’t think I was fierce competition, they would worry about me once they saw that I could cook.

It’s natural. People are curious about how I do things. Even my friends find it interesting to see how I achieve things in the kitchen. Fans want to know how I put on my makeup. I’ve thought of putting on makeup or cooking on YouTube – so people can see how I do things (as someone who’s legally blind).

Q: What are some of the accommodations that people who are blind use when they cook? What are some of the limitations that folks who have low vision encounter when they engage in the culinary arts?

A: There are things like talking thermometers. In my home kitchen, I cook by myself and with my husband. Knowing where things are is important. I ask him not to move or remove things from where I’ve placed them.

Cooking in a commercial kitchen isn’t impossible for a blind person, but it’s difficult – it has challenges. Food has to be prepared in a short amount of time. A visually

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Master Chef

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A: I envisioned it being a collective voice. When policymakers were making decisions, they were hearing from parents. They were hearing from professionals. They should hear from us. ASAN was designed to be a source of political power and to have a sophisticated understanding of public policy as well as research and service provision that could put us on par with comparable advocacy efforts within the parent and professional communities.

Q: Why was ASAN successful in shutting down the ransom notes campaign?

A: We were clear that this was not going to work if we were only blogging about this and speaking to ourselves. We sent out action alerts where we provided not just the email and phone number for the NYU Child Studies Center. We also managed through various intelligence efforts to get the email addresses of several of their large donors. So we hit them where it hurts. We managed to get media coverage in The New York Times, The Wall Street Journal, The Washington Post. The most important thing we were able to do was tap into the broader cross-disability community. The first group we got on our sign-on letter was ADAPT. After that, getting groups like NCIL, AAPD and TASH (an international advocacy association of people with disabilities and advocates) on board was pretty simple.

Q: What are ASAN's main priorities?

A: We’re very interested in pushing the boundaries of the Olmstead decision. Very often, states just rebrand institutions as community-based settings. Two years ago, Missouri decided to take the residents of an institution and put them in several large group homes on the same grounds of the institution. They were going to call it a gated community. We were fortunate that we and other organizations were able to convince CMS (the Centers for Medicare & Medicaid Services) to refuse permission. So some of our advocacy is centered on urging CMS and state governments to come up with meaningful definitions of home- and community-based services that talk about the rights people have. Are people free to invite visitors? Do people have the freedom to go to bed when they want? If you’re 45 years old and you have a bedtime, you’re living in an institutional environment, even if there are only two or three roommates there.

Right now, most autism research funding goes toward causation and cure. We don’t believe in the idea of cure. There’s not going to be a magic pill that

Claypool says some CILs have lost significant funding by losing the HCBS service provision.

“CILs will have to rejigger their business models if they want to provide PCA services. The CILs were robust but (were) based on a business model of the state paying for agency services. They were funded like nursing homes. Consumer direction doesn’t need that much staff attention. It needs a fiscal intermediary and modest support on how to arrange PCAs. Really, you are just a fiscal intermediary providing case management.”

The Disability Rights Education and Defense Fund and the National Senior Citizens Law Center recently issued a guide that should prove valuable for state-based My Medicaid Matters coalitions and other disability rights advocates. The guide, “Identifying and Selecting Long-Term Services and Supports Outcome Measures,” focuses on outcome measures based on individual experience, because a beneficiary’s experiences are the best starting point for judging whether systems are performing well. The guide discusses existing and in-development quality measures, presents criteria for selecting LTSS outcome measures, suggests methods for building LTSS knowledge and infrastructure, and promotes steps advocates can take.

Navigating Medicaid LTSS and HCBS and advocating for consumer direction in state Medicaid plans is a challenge, yet helping people with disabilities live in their own homes and communities rather than nursing homes is a priority in the disability rights movement.

The best way to ensure sufficient home- and community-based services (HCBS) in your state is to be at the negotiating table to help shape the Medicaid plan. For those stakeholders not invited to the planning table, make sure your state is including funding for HCBS/LTSS in its Medicaid plan and delivery system.

And if your state is not following the ADA and Olmstead guidelines, I urge you to file complaints with CMS. If you still don’t get results, go ahead and sue your state – you can do so under ADA and Olmstead law.

Janine Bertram Kemp is a writer, advocate and president of the Disability Rights Center. She also is a member of ADAPT.

WRITERS WANTED

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‘Jersey’ Sure Has Come a Long Way

By John M Williams

To quote 27-year old Matthew “Jersey” Thomas: “I am the luckiest man in the world.”

When asked why he thinks that, he replied: “I have a job. I am engaged. I won thousands of dollars (on a horse race), and I was recently promoted.”

A native of New Jersey, Thomas recently received his doctorate in economics from Penn State University. Earning a Ph. D. had been his goal for 10 years since starting college in 2003. Along the way, he graduated in 2007 magna cum laude from Michigan State University with a Bachelor of Arts in economics. Two years later, he received his master’s degree in economics from MSU.

“‘Jersey’ is a braggart about his accomplishments, but they are real,” said Terrence O’Rourke, who roomed with Thomas for five years. He came up with the name “Jersey” because every one of Thomas’ sweaters and sweatshirts had that name on it. Thomas was born in Jersey City in 1986.

Thomas likes being called “Jersey”; he wears the nickname proudly. Most of his classmates and his friends and family call him that. He and his family spend two weeks on the Jersey Shore every July. They have been going there since Jersey was 1 year old.

“‘Jersey’ has a right to brag,” said Thomas’ fiancée, Maureen McCormick. “For someone with multiple disabilities, he has achieved much.”

McCormick met Thomas three years ago when her brother Larry brought him home for Thanksgiving weekend. She was impressed by his willingness to play touch football even though he has been blind in his left eye since birth. They have been going there since Jersey was 1 year old.

Thomas does not like to talk about his blindness, his 40% hearing loss or his articulatory problem. “I am measured by my ability and not my disabilities,” he said. Nor does he like to dwell on the past challenges his disabilities posed. His enthusiasm disappears when he remembers his early school years.

“The public and private schools in Jersey City were not intellectually equipped to educate a student with multiple disabilities,” said his father, Randolph Thomas.
During her roles as an Oxford scholar, a Yale law student and the daughter of a Florida family of means, Saks experienced repeated, sometimes horrific, hospitalizations in England and America.

In one milestone episode, we see her as an intense law student, spiraling into one of her episodes while in her professor’s office. She climbs out onto the roof and fashions herself a belt from the telephone wire she finds there. The compassionate professor invites her home to have dinner with his family, but inevitably, they wind up at the emergency room. We feel both the anguish of her life spinning out of control along with the concern of those around her.

When we read of her as a determined psychotic in the emergency room who is restrained with leather straps on all four limbs and has medication forced down her throat, her terror is ours. This is only one of countless episodes of her spiraling into and out of her psychotic episodes, and again and again, we see her resilience as she resumes her therapy sessions and takes the medication essential to maintaining her mental health.

When her psychotic episodes are triggered, she babbles incoherently with engaging word play, twirling while singing nonsense ditties, or muttering that she fears she must be dangerous, identifying herself with various murderous criminals who have been in the news.

And yet, again and again, she is a survivor. She is brilliant; she won a MacArthur Fellowship, also known as the “genius grant,” and currently is a law professor in southern California.

She writes poignantly of the stigma surrounding mental illness and her empathy with patients who still are sometimes mistreated. She has firsthand knowledge of the humiliation and degradation that some patients still suffer. Despite being labeled as essentially incapable of making any contribution to society, she has proved that, with proper treatment, a person with schizophrenia can have a brilliant career, friendships, love -- a life.

Saks writes with passion and stunning clarity. What makes this book well worth reading, however, is her honesty. She exposes herself entirely -- including her delusions and insecurities -- and does so with the clearly fervent hope that her candor will help others better understand and more appropriately treat others with mental illness.

Deborah Kendrick is a newspaper columnist, editor and poet. She can be reached at Kendrick.deborah@gmail.com.
Thomas said school bored him because his teachers treated him as though he was not even there most of the time. As a result, he was a C-minus student and was not motivated to study. When his family moved to Lansing, Mich., in 1999, Thomas met “a most remarkable teacher.” That teacher was Sarah Campbell.

“I had read Thomas’ school transcripts before I met him,” Campbell said. “I had a totally different picture of him when I met him.” She said Thomas impressed her when she asked him what his goals were.

“I want to attend college and earn a degree in economics and earn $100,000 a year when I reach 30,” he said.

“I was floored,” Campbell said. Instead of spending 30 minutes with Thomas, she spent 90 minutes. She learned that the schools in New Jersey had not given Thomas the technology, the counseling and other services to which he was entitled.

Campbell believed that given the proper tools and guidance, Thomas could be successful. She worked with the school, Thomas, his parents, a speech therapist and an audiologist on his individualized education program (IEP) diploma. She encouraged Thomas to get involved in the math club and chess club. The athletics coach convinced Thomas to become involved in softball as a third base coach.

The school printed materials in 16-point type, so he could read them. He recorded his classes using a handheld tape recorder. His teachers wore a microphone, and Thomas wore a headset. He went to speech therapy twice weekly and became interested in acting. In his junior and senior years, he had small parts in the school’s plays. Academically, by the end of his freshman year he was 15th out of a class of 191. When he graduated from high school, he was ranked fifth out of a class of 248.

In the fall of 2003, he attended MSU on an academic scholarship. He graduated in 2007.

“College was my salvation,” Thomas said. “I had all the assistive technology and student services for disabled students I needed.”

He made friends with blind students, deaf and hearing-impaired students and students with speech impediments. He joined the chess, accounting, acting and foreign language clubs. He even tried out for the baseball team but didn’t make it. “I am about as athletically coordinated as a 70-year-old-man with arthritis in both knees,” he said, laughing.

When Thomas graduated in 2007, he was offered jobs with Arthur Andersen and Co., General Electric, Apple, Ernst & Young, and a dozen smaller companies. He picked Goodrich. After 18 months, he left to attend Penn State University. The company promised to hire him back when he earned his doctorate. While at Penn State, he worked for Goodrich part time.

“In my time with Goodrich, I never heard a discouraging word about my disabilities,” Thomas said. He believes he was judged on his ability. “I would not work for a business that would discriminate against people with disabilities.”

Thomas has had numerous job offers but has not decided which one he will accept. He wants to be challenged personally, mathematically and economically. He wants to see more people with disabilities with a college education hired in responsible and prestigious positions.

Thomas rejects the notion that he is a role model for people with disabilities. He does not consider himself to be disabled. He believes he is physically limited in certain areas but that those limitations do not make him a disabled person.

“I am what I am,” he said.

As a rabid horse race follower and a cautious gambler, he also won thousands on the Preakness Stakes this year.

“I will never be as lucky as I was picking It’s My Lucky Day to come in second,” Thomas said. The horse, a longshot, did exactly that.

Thomas’ heroine is Helen Keller. He believes that as a deafblind woman, she did more to educate the world about the abilities of people with disabilities than any person with a disability who ever lived.

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Sometimes facing what scares us the most, entering the environment that scares us most, may mean going for a walk. In my case, leaving my home scared me the most. And the walk? Well, it actually was something of a march.

I once asked a close friend why people ask me or encourage me to write about my life -- particular times in it, to be precise. “Because it’s true,” she said. As surprising as her answer might sound to some, it made sense to me. Pretty much anything about my life that is, in any way, extraordinary or unique is so in spite of me, not because of me. I am well aware of this fact. Life happens to us whether we like it or not.

And so it was that in 1985 after being held up and shot a year earlier and then held up at gunpoint and not shot some six months later that the idea of leaving my house for any reason (I lived in New York City’s Lower East Side at the time) was out of the question, or so every fiber of my being -- physical, spiritual, psychological and emotional -- had concluded.

But, thankfully, my friend Dane lived upstairs from me. Then, as now, he was a loyal, loving friend, and then, as now, he had an uncanny talent for identifying what was necessary to fracture, or begin to fracture, the viselike disabling grip some of the more difficult things in life have on us. In my case, it was my heartfelt reluctance to step foot out of my house.

Just days after the second holdup, Dane visited me. This is how I remember it:

“It’s time to march,” Dane says. “You’ve backed I don’t know how many people through hard times. Today’s your turn. I’m backing you. We’re gonna march.”

“Yes. We’re going for a walk. We’re going out and march. You have to move. All I want you to do is stay with me as best you can. You don’t have to talk; just keep walking.”

I am frozen in place, terrified. I can feel my body and my veins ice over. I can barely move. But I know that I trust Dane, and I know that I can go out the door with him although I don’t know what will happen to us. Here I am, the man who used to protect his friends, male and female, thoroughly stripped of all his armor, incapable of protecting himself, much less anyone else.

Dane persists. “Come on, Pete. You can do it. Look at what you’ve been through. We’ll just go walk. We don’t have to stop anywhere, talk to anyone. We’ll just walk. March.”

I nod.

A few minutes later I am following Dane west on Houston Street. The day isn’t just hot, it is sticky-hot, and I am sweating. My eyes stay glued to Dane’s back. Just keep moving and don’t stop, I think. I watch his stride. It is powerful, defiant. I know this man is my friend. He’s like a brother, and he loves me, and he wants to keep me alive, I think. We don’t talk because we don’t have to talk – because Dane probably knows I can’t talk anyway. We just walk. We march.

Dane is in front of me, leading the way; my eyes cling to the comforting presence of his back. The joyous dancing scents of Italian food fill me and provide brief respite from the terror. The scents of fruit
Father, Son

Continued from page 11

ried a prison term of more than 60 years, Cubby was found not guilty of all charges after a drawn-out, highly expensive trial. Today, Cubby, who has a girlfriend, is still interested in science, though he is no longer involved with explosives. He and his girlfriend speak about Asperger’s to young people.

John Elder Robison was born in Athens, Ga., and grew up in the 1960s before people knew of Asperger’s syndrome. In addition to his other memoirs, he wrote the book “Be Different.” His business, J. E. Robison Services, restores and services European cars. He is on many committees and review boards, including the International Society for Autism Research, the Interagency Autism Coordinating Committee of the Department of Health and Human Services, and the Centers for Disease Control.

In a recent telephone conversation, John Elder Robison and Cubby touched on a wide range of topics from how Asperger’s is both a disability and a gift to the difficulty of reading social cues to being a natural storyteller. Excerpts of that conversation follow. (The interview with John Elder Robison appears first; the chat with Cubby is next.).

John Elder Robison:

Q: You first heard about Asperger’s when you were 40. You were in a restaurant with a friend who said you might have it. What was it like for you at that moment and when you were formally diagnosed with Asperger’s?

A: I didn’t know what Asperger’s was when I first heard about it. The only kids with autism who I knew about didn’t talk at all. (But) I’d felt different always, and I didn’t know why. Learning that I had Asperger’s made me understand – it made my life better.

Q: What made you become a writer? What sparked you to tell your (and Cubby’s) story?

A: I love to tell stories. People say I’m a natural storyteller. I was asked if I’d ever try writing. I said, “Well, sure!” It’s easy to tell stories. I wanted to speak about being different, having Asperger’s and parenting. I basically sat down and wrote “Look Me in the Eye.” I told the story of being a father in “Raising Cubby.”

Q: Would you talk about the difficulty that people with Asperger’s have with reading social cues and how, especially as children, they can be bullied?

A: People with Asperger’s have difficulty with social cues. Kids on the (autism) spectrum have a hard time reading the feelings of other people. People say teaching social skills to kids is complicated, but it’s basic. It’s teaching manners, teaching them to care. When Cubby was a kid, I’d see him getting into a tussle with another kid. I’d say (to him): “Say, that’s a nice toy! Can I see it?” Don’t say, “I like elephants!” Don’t grab it out of his hand. It’s basic stuff.

Kids with Asperger’s a lot of times are singled out – they can be mistreated because it’s an invisible disability. If you look at a blind guy, you can tell that he doesn’t see facial impressions. But, looking at Cubby or me, you don’t expect us to be oblivious (to social cues, such as body language). You assume that we’re deliberately ignoring you. Another thing: People with Asperger’s often have clear, precise speech. You don’t expect them to say the (socially) wrong thing.

Q: You’ve said that there’s too much talk (of Asperger’s) as a disability. Would you talk about how you view it as not only an impairment but as a difference -- a gift?
Father, Son

A: Yes, Asperger’s is a disability. I wouldn’t dismiss the disability that people with Asperger’s or autism (especially those on the spectrum who are nonverbal) deal with. But it (Asperger’s) also makes us different – it makes us who we are. People with Asperger’s have a greater ability to focus -- to concentrate -- to systematize. It gave me insight into electronics and rock ‘n’ roll when I was younger that contributed to my success. It was something I wouldn’t have been able to do if I was an ordinary (without Asperger’s) kid. [Robison created electronic effects for the band Kiss.]

Q: What is your concern with current autism research?

A: Hundreds of millions of dollars have funded promising original research into promising therapies for intervention for autism. Yet this knowledge isn’t getting out to clinicians and others who help those who need the help. A clinician anywhere ought to be able to find information -- a guidebook -- on different aspects of autism -- from challenges facing people on the spectrum who don’t speak to the gastric problems of some people with autism.

Cubby Robison:

Q: What does having Asperger’s mean to you?

A: Having Asperger’s is the way I am. It’s how I’ve always been since I was little. Before I was diagnosed with it, I knew I was unlike the other kids. Asperger’s put a name to it. It wasn’t a revelation. I already knew what was there. It’s hard to describe feeling different. I just knew that some people were my sort of animal, and that everyone else seemed like a different species. It was apparent at an intuitive level. In elementary school, one friend was like me. Two friends were not like me. To me, there was a clear difference in how we seemed to think.

Q: Would you describe your feelings about your trial (for making explosives)? Thankfully, you were acquitted. But it must have been highly stressful.

A: I thought the trial was going to be the end of my life! I thought they’d put me in jail for 80 years! I wondered: Would I have to be sent away forever to another country? I wasn’t prepared. I didn’t complete Eagle Scouts because of it. I couldn’t go to school for a semester. I was paranoid. To say I was stressed is an understatement! I wasn’t trying to hurt anyone.

Q: You and your girlfriend, who also has Asperger’s, speak to groups about love and relationships. What’s dating like for folks with Asperger’s?

A: I tend to think people with Asperger’s and autism flock together. You get along better. My first and present girlfriend both have Asperger’s. We think similarly ...The skills of small talk necessary with neurotypicals (people without Asperger’s) aren’t as necessary with our own kind. We often have the best luck meeting people and socializing in special interest clubs (such as computer or chemistry clubs) instead of at parties.


Ne’eman

Q: What should be the guiding principles of those creating and funding public policy affecting people with autism?

A: We prefer that the autism service provision system doesn’t repeat the mistakes the disability service provision system has made and begun to move beyond. The big priorities are community inclusion, equal protection of law, hearing self-advocate voices. Let’s focus on empowering us to have happy lives as autistic people, rather than trying to force us to pretend that we’re not autistic people.

Mike Ervin is a writer who lives in Chicago. His blog, “Smart Ass Cripple,” appears at smartasscripple.blogspot.com.