

BY SHEILA ENGELMAN

By nature, most expectant parents anticipate with absolute certainty that their soon-to-be-born child will be smart, talented, well-behaved, a credit to the family, and possess the best features of each of them. For Estee Klar-Wolfond and her husband, Henry, all this seemed to be true when their son, Adam, was born five years ago. But this idyllic picture changed dramatically 18 months later when Adam was diagnosed as autistic.

"When I first heard the word *autism* I was in disbelief," Klar-Wolfond says in response to her initial reaction. "For me, Adam was a version of our *normal* as I knew him as no other way to be. It was Henry, who has four other children, who expected Adam to respond to him in ways his other children did, and Henry who had a conversation with another parent with an autistic child. Henry found in that conversation some similarities between that child and Adam."

When asked for a definition of autism, Dr. Nehama Baum, director of the MukiBaum Treatment Centres for people with multiple developmental and emotional disabilities (including autism), reveals that if she had one, she'd be rich. Autism is so multi-dimensional,

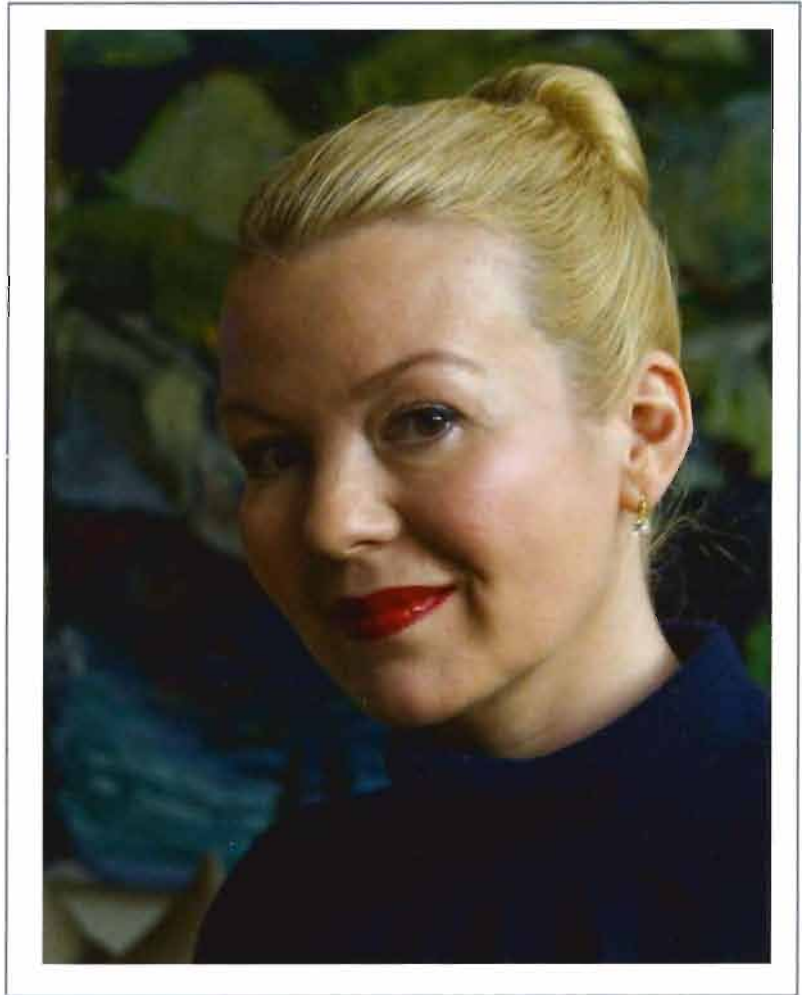


Photo courtesy of Estee Klar-Wolfond

ESTEE KLAR-WOLFOND

speaking out

and its manifestations so varied, that it defies description, she says. At one end of the spectrum, autistics can be severely mentally challenged, non-verbal and almost non-functional in the usual social sense. At the other, they can be highly intelligent, creative, attend university, and lead productive lives, albeit with some unusual behavioral patterns. Common denominators can include difficulty in sensory processing (i.e., not liking to be touched and sensitive hearing that can make loud noises painful) and difficulties in social interaction.

Dr. Morton Ann Gernsbacher, professor of psychology at the University of Wisconsin-Madison, and president of the Association for Psychological Science, says that autism is defined by "atypical communication and more

focused-than-average interests. Autistic traits have most likely existed since humanity's origin."

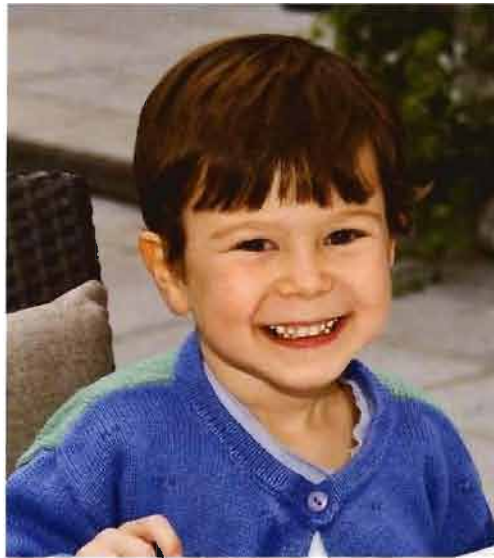
Adam was diagnosed in December 2003; within a month he was involved in 40 hours a week of therapy, which has since been discontinued after his parents learned more about autism and the experiences of autistic people. After an extensive and exhaustive search for the right therapist, the Wolfonds found the person they trusted to work with them in providing their son with the activities and tools he needed to progress toward achieving his potential. This came about from "meeting and studying and learning about how autistic individuals learn naturally, but sometimes differently, from other people," Klar-Wolfond explains.

"On and off for two years, we brought in various experts and always remained dissatisfied. As long as Adam was going to be viewed as a pathology rather than a human being, I would always keep moving on, learning and struggling to trust Adam on my most doubtful days. As he gets older, everything becomes less of an issue. He's a good boy and is just like other kids, but with differences.

"We thought, despite Adam's atypical responses to other people and to toys, that he was gifted," she says about her son's early months. "Adam began reading at the age of 11 months and had been diagnosed with hyperlexia. (According to the American Hyperlexia Association, hyperlexia is "somewhat similar to autism and is manifested by a precocious ability to reach words far above what should be expected at the child's chronological age or an intense fascination with letters and numbers as well as significant difficulty in understanding verbal language and difficulty in socializing and interacting with people.") We have pictures of him reading Shakespeare's

Henry VIII. Adam knew how to count, knew his alphabet, shapes, colors at that age and I tested his reading skills at 16 months. He could read words like *whale* with the silent *e* and he was reading out loud the titles of book spines from his playpen that were next to it. He would hoist himself up, hold on to the rail and read *Gotham*."

She criticizes what she calls the "pathological view clinicians and the medical profession have of autism. It is



Klar-Wolfond's son, Adam.

not unlike what the deaf, blind, cerebral palsy, and Down's syndrome communities have been through—an over-medicalized view of disability," she explains. "With all disabilities, an ethical and sociological dialogue had to happen before any stigma was reduced and better accommodations and education were realized. The same is going on in autism, but the political debate is raging—from politicians to large autism societies and among families themselves—should the disabled (or, in this case, autistics) be seen as whole and have a right to exist as disabled/autistic people? Or, should we prevent and cure autism at all costs and despite what the autistic community has to say about their own autism which many describe as challenging but is a funda-

mental part of who they are or a 'way of being.' I discovered that only in autism are the autistic excluded from boards and government policy committees on autism. This is discrimination."

"I have similar beliefs to Estee," says Dr. Baum, "and don't use behavior modification (a widely used form of therapy that involves rewards, often food). I'm very humanistic and believe that if we provide the right environment in a way that is supportive rather than behavioristic, we can achieve success. Estee is really a fighter; she has lots of energy to push forward the cause of children with autism. She is a huge advocate for people with autism to have the right to be who they are and that society must accept them."

In 2006, as a result of her research and the input provided by the extensive network she developed with autistic people of all ages and their families, Klar-Wolfond established The Autism Acceptance Project (TAAPProject). Her husband provided moral support, she says, but explains that the undertaking was "self-directed. I met a lot of autistic adults and parents who agreed that this is not about curing autism, per se; it's about respecting the right to be who you are, valuing all humanity. It's about acceptance."

The organization's mission statement explains that it is "tapping into human potential and dignity and is working towards achieving acceptance and tolerance of autistic people in society. The Autism Acceptance Project will bring forth a different and positive view about autism to the public in order to create tolerance and acceptance in the community and to empower parents and autistic people."

On first meeting, Klar-Wolfond seems to be a typical upper-middle-class young wife and mother, well edu-

Photo courtesy of Estee Klar-Wolfond

cated, with an interesting and varied professional background, living a life of comfort. Dressed casually, she is gracious, affable, and speaks openly and lovingly about her life and her family. She has a beautiful smile and her face literally lights up with even a passing mention of little Adam. As she describes her current activities, which primarily revolve around her son and the challenges faced by autistics, her steely determination to secure acceptance of, and accommodation for, the disabled comes through quite vividly.

Jamie Gold, a family friend, calls her a "star at the cutting edge of the disability movement. Autism is a very complex condition that defies simple solutions. At the core, Estee's advocating for

a TAAProject newsletter. Included in the newsletter are articles and reproductions of art by autistics. Included in the October 2006 newsletter is a piece entitled "Adam's World to Mine," written by Henry Wolfond's son, Max, who is now 18 years old. Calling Adam "a heluva gift," Max writes about his half-brother with compassion and love. Much to his stepmother's pleasure, Max served as a "shadow" for an autistic teenager at an inclusive sleep-away camp north of Toronto.

Klar-Wolfond says she has also been writing a book "on and off for a couple of years. Primarily my writing is about our journey, and the ethical and political issues facing Adam's community." She has also curated exhibitions of art pro-

and how to reason," she says. She was an artistic child and says her greatest inspiration came from her fifth-grade teacher, Mrs. Quinlan, who was an avid feminist and recognized her abilities in music, art, and writing. "She inspired me to keep writing," Klar-Wolfond recalls. "I liked her. She was about four feet nine inches tall and would stand on her desk and preach about feminism. Nowadays, she wouldn't be permitted to be so political in class."

Klar-Wolfond went on to earn an undergraduate degree in fine art history at the University of Toronto. After graduation, she became assistant curator at the then brand new Mississauga Art Gallery. "I was very fortunate to work with Valerie Greenfield, the curator. We

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basic human rights for her son and other autistics to be included in decision-making about their lives. It reflects her core belief in the dignity of all people."

Dr. Gernsbacher agrees, adding that "working from a disability rights perspective, many of Ms. Klar-Wolfond's efforts have been toward increasing awareness of autistic individuals' fundamental rights: equality and dignity."

In order to promote TAAProject, Klar-Wolfond has made presentations to government agencies, families of autistics, and medical professionals, written a number of magazine articles, and contributed an essay to *Between Interruptions: Thirty Women Tell the Truth About Motherhood*, a book recently released by Key Porter Books (a select number of the essays have been reprinted in the *Globe and Mail*). She maintains a regular blog called "The Joy of Autism" and publishes

duced by autistics and presented a lecture called "The Joy of Autism: Redefining Ability and Quality of Life," which was internationally received and attended.

Although she wasn't trained to be a fighter, Klar-Wolfond is calling upon her innate talents and her previous professional experiences to help her battle against misinformation, ignorance, and fear of those who are different. She is also fighting for the basic human rights of people who don't fit the norm.

The only child of Helen and Michael Klar, respectively a student of music and a retired manufacturer of semi-conductors, she was born in Toronto where she spent her early years. Later on she also lived in Mississauga. "My father was a highly ethical man who taught me philosophy

exhibited works by some of the leading Canadian artists, including Michael Snow and Noel Harding. The gallery is not large, but earned credibility thanks to the quality of its exhibits which it still maintains." When Greenfield left the position, Klar-Wolfond took over but then also left to earn a graduate degree in German Expressionism.

Her plans to remain in Europe after earning her degree were altered when her mother was diagnosed with renal cancer. She returned to Canada to be with her parents and started working at the Lonsdale Gallery in midtown Toronto. The gallery was owned by Chad Wolfond, Henry's brother. Klar-Wolfond met her future husband in 1996 and they married five years later. Henry, a lawyer by training, is chairman and co-founder of Bayshore Capital Technologies, an investment firm that is

focused on the application of information technology in financial services. He and his brothers, Chad and Greg, donated the lead gift for what was to become the Wolfond Centre for Jewish Campus Life at the University of Toronto in honor of their parents, Pedie and Melvyn. Henry will be serving as co-chair, with Fran Sonshine, of the 2009 UJA Campaign in Toronto.

Klar-Wolfond subsequently left her position at the Lonsdale Gallery to serve as director of corporate development and marketing for the Arthritis Society—until Adam's birth. "I was a good marketer," she says. "I garnered a lot of skills and became a good fundraiser by default." Now, as founder and executive director of TAAProject, she calls on these skills to foster inclusion and understanding of people with autism as well as a "more empathetic society towards individuals with disabilities.

"I have been meeting with politicians and raising the 'disability rights' issues of autism, namely the present exclusion of autistic

U.S., and recently I lectured at MIT."

Klar-Wolfond expresses disappointment that the autism societies, which purport to speak on behalf of autistics, do not have autistics on their boards or at the forefront of their organizations. The TAAProject board does include autistic adults and parents of autistics.

In addition to her current TAAProject activities, Klar-Wolfond is looking forward to completing her book within a year, and is planning another



(l-r) Estee, Adam and Henry.

"I do not like the insinuation that disabled or autistic people are a financial burden on society, as reflected in our recent Senate Committee Report *Pay Now or Pay Later*. I like to focus on investing in sensitivity training and a social understanding of disability as a path to inclusion and acceptance. That investment made today will pay dividends in the future in the way that all people with disabilities are taught and included in all facets of the community.

"As we continue to learn more and more about how each of us learns," she says, "and the unique challenges that many autistic individuals face, we have the potential to become better teachers and a more sensitive society. I am hopeful and excited for Adam's future. I believe we will see more autistic people attending colleges and universities in the future, not because we have cured autism per se, but because we are learning what *accommodating autism* really means. I believe we are learning to value every human being. Adam has, at the very

Photo by Al Gilbert

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people from all boards and policy committees about autism," she says, "and the need to know how autistic people can participate as they will require modifications for participating on such committees. We speak to the Autism Society of Ontario and to the Geneva Centre for Autism, who acknowledge the important issues that TAAProject raises. We do a lot of speaking in the

lecture series. She is also involved, as a board member, in the

: School that Adam attends.

"I support inclusive education, varied methods, the right to choose and access to affordable assistive communication devices, and trained people to teach using them," she says when asked about the presumed high cost of educating the disabled.

least, taught me that."

Judging by her unconditional love for her son, and her limitless determination to see him and other autistics treated with dignity and respect, it seems evident that Estee Klar-Wolfond won't rest until this goal has been achieved.

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