# Asperger's Syndrome and the Public Consciousness

Dr. Irma Jacqueline Ozer (Ph.D./J.D.)

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#### Reader Testimonials

Dr. Irma Jacqueline Ozer has enriched the literature on the Autism Spectrum with her book, Asperger's Syndrome and the Public Consciousness.

Dr. Ozer has several sections in her book. The Psychology section provides the reader with a scholarly review of past and present works on Asperger's and Autism Spectrum Disorders. I highly recommend this as required reading for anyone who works with people on the spectrum, as well those who are on the spectrum themselves, families and friends.

I consider her work a masterpiece!

Ellen Lamonoff, RN, MS Director of Nursing Services Westchester Jewish Community Services Serving People with Special Needs

Dr. Ozer's courageous and inspirational book is a must read for everyone to

connect their life passion and purpose. The combination of academic rigor blended

with practical insightcalls each of us to dedicate ourselves toward improving the quality of life and social justice for others.

Dr. William W. Arnold Professor of Business Pepperdine University, Malibu, California

I found the book to be extremely informative, especially in areas with which I am not familiar. I found Dr. Ozer's story to be most powerful in that she was able to triumph and achieve her goals. She is certainly a role model for those who suffer with Asperberger's.

Cal Flachner LC

I found Asperger's Syndrome and the Public Consciousness to be a fascinating and valuable synthesis of various aspects of the condition. This synthesis includes the writer's personal experience and her extensive research into the subject, as well as providing valuable corollary viewpoints arising out of Dr. Ozer's background in law and the arts. This broader perspective allows the subject matter of the book to move beyond the usual personal or scientific focus that informs most books on autism spectrum disorders.

Sincerely, Kim Rich Norton

## Acknowledgments

I owe Dr. Dermot Frengley a debt of gratitude for first giving me a diagnosis of Asperger's Syndrome and setting me on the path to the creation of this book.

I thank Professor Michael Perlin of New York Law School for his years of encouragement, and for the knowledge and legal consciousness with which he has enriched my life.

I thank my mother who suffered through my crises and was always there for me in the worst of times. Even when she was demented, she still told me, "you are remarkable."

Finally, I thank my deceased father, a Reform Jewish rabbi and professor, whose last wish was that I should write. I have written and published since 1986, and I will continue to do so.

The remaining people to whom I owe acknowledgments will be included in either my section on Wellsprings of Consolation or in Beacons.

#### **Preface**

In 2003 I was taking a graduate course in Abnormal Psychology at John Jay College. A section on Asperger's Syndrome was included in our textbook. I noticed symptoms that I have, and I began to research Asperger's Syndrome in earnest. At the same time I watched episodes of the hit series *Law and Order* as well as its offshoots, *SVU* and *Criminal Intent*. The depictions of persons with Asperger's Syndrome were terrifying to me. The impact of those *Law and Order* episodes was so powerful that all I could think of was the opinion millions of viewers must have of people with Asperger's Syndrome.

I wrote and had published scholarly works on epilepsy and the need for reparations for African Americans. In these articles I advocated for both the epilepsy and the African-American populations. I could be objective because I am neither a person with epilepsy nor an African American. Thus, I was able to be a legitimate scholar. I cannot be objective regarding Asperger's. Syndrome, because I belong to this population. I therefore designate myself for the purposes of this book as an Aspergian Explorer.

The book will begin with my own story. The autobiography will be followed by tributes to authors whose books about their lives with Asperger's Syndrome inspired me to regard them as Beacons.

From there I will proceed to the trifocal part of the book. In the first section, the findings of mental health professionals will be discussed, based on characteristics of persons with Asperger's Syndrome. The purpose of this section is to present articles and segments of books in accessible fashion.

In the second section, I will proceed to the legal focus, which consists of three components. The first component will be in the form of a short play depicting a trial

(The Asperger's Syndrome Community on Trial), in which the "Prosecuting Attorney" will use as witnesses authors of articles on criminal cases involving violent acts allegedly committed by persons with Asperger's Syndrome. The "Defense Attorney" will present as witnesses authors of books and articles, which indicate that individuals with Asperger's Syndrome rarely commit violent crimes. The "Judge" will then render a decision. The second component of the legal focus will be the impact of the Americans With Disabilities Act on employment issues faced by persons with Asperger's Syndrome. The third component will cover personal accounts of individuals with Asperger's Syndrome in relation to their work experiences, prior to and since the passage of the Americans With Disabilities Act.

In the third section, the depiction of Asperger's Syndrome in the media will represent the conclusion of my trifocal exploration. This extensive section will include discussions of various articles, a novel, movies, and television (both reality and fiction).

In each of these three sections I will address the impact the material may have on the public consciousness. The impact may be positive, negative, or non-existent.

In the Conclusion I will suggest ways in which any negative impact on the public consciousness may be combated. I will also discuss the need for a unified Autistic Spectrum community.

This book is intended to be used as an ancillary text in college classrooms, in continuing education programs, and in on-line courses. It can also be an aid to mental health professionals with limited knowledge of Asperger's Syndrome. Moreover, the aim of the personal accounts and trifocal approach is to provide a broad spectrum of material on AS to persons who have been recently diagnosed with Asperger's. Above all, I hope that those of us who live with Asperger's Syndrome, as well as their families, will find their lives enriched by the book's content.

It should be noted that when I refer to the "public consciousness," I mean all classes—from the most intellectually accomplished to the average person. In addition, the readers should be aware that I use real names of persons and organizations in many cases. In other cases, however, I alter the names to ensure the privacy of all concerned.

## My Story: On Wings of Asperger's

## Prologue

How do I begin to tell my story? Asperger's Syndrome has shattered my dreams. It has taken from me, over many years, friends and professional opportunities. Yet, Asperger's Syndrome has given to me the wings to transform my pain from a prison into poetry. Now I sit at my computer, a sixty-five year old woman with Multiple Sclerosis. The fatigue is so great that just an hour of effort exhausts me. It is a malaise that drains me, as if my body were an hourglass with the sand of vitality flowing ever downward. Wondering if it is worth the effort to write this book, the answer spurs me on: YES!

As the poet Robert Frost wrote in "Stopping by Woods on a Snowy Evening,"

The woods are lovely, dark and deep, But I have promises to keep, And miles to go before I sleep, And miles to go before I sleep.

I am well aware that many brilliant and inspiring books have been written by authors on the autistic spectrum, who have achieved far more than I have. Still, I know that my multidisciplinary approach to Asperger's Syndrome offers a rather unusual perspective. My biography will not be a chronological presentation, but rather a narration based primarily on the core symptoms of Asperger's Syndrome.

## "Something is wrong with my baby"

Those agonized words are repeated by mothers everywhere, who must face their child's disability. Like many autistic babies, I was unresponsive to hugs and kisses. I responded only to the sounds of the birds singing.

My mother had to suffer the fact that her baby did not eat or defecate and had to be force-fed. When she expressed the belief that I had a non-functioning thyroid, physician after physician scoffed at her. They maintained that she was neurotic and advised her to go back to her kitchen.

Finally, when I was sixteen months old, my physician uncle managed to obtain an appointment for a consultation at Duke University Hospital. By that time I was a

bloated blob with a lolling tongue. The diagnosis was "incipient cretinism." A cretin is an infant without thyroid function who grows up to be a dwarf with a large head and mental retardation. In my case it was found that I had only a vestigial thyroid gland. It is relevant to note here that contemporary research, specifically by Raphael Kellman, M,D., suggests that hypothyroidism may be correlated withautism.

I was given thyroid replacement hormone, and within one month my appearance was normal. The endocrinologist gave my mother the following prognosis: "Your child will be physically normal, but most likely she will be mildly retarded for the rest of her life." I have always had physical problems with coordination. In adulthood, my IQ was found to be very high. In fact, at the age of eleven I was reading books on abnormal psychology and understanding every word. However, as a toddler I was still mildly retarded and unresponsive to people, including my parents. At that point it was difficult to say where my thyroid condition left off and my autism spectrum condition began.

The pain and desperation of having a disabled child that my parents endured is familiar to the parents of autistic/Asperger's children all over the world. There is the fear that one of the parents had faulty genes or did something to cause the child's condition. Although we who are on the autistic spectrum suffer in childhood as well as in adulthood, our parents usually suffer along with us and live with the anxiety of what may happen to us. Since there is strong evidence that autistic spectrum conditions run in families, parents may be diagnosed with Asperger's after their children receive their diagnoses.

## My Parents: Did They Have "Shadow Syndrome?"

"Shadow syndromes" exist where some, but not all, symptoms of a mental or developmental disability are present. John Ratey, M.D. and Catherine Johnson, Ph.D., wrote a book on shadow syndromes, which covered many disorders, including autism.

Looking back, I have no doubt that my deceased father had the shadow syndrome of Asperger's. My mother, until she became almost totally demented in her nineties, also evinced symptoms of Asperger's. My Departed Father

My father, Rabbi Dr. Charles L. Ozer, was born in Poland in a Jewish *shtetl* (ghetto). His parents were simple and uneducated. He also had a brother who eventually became a salesman with modest success. When my father was in his early teens the family emigrated to New York.

It soon became evident that my father was "special," very nervous and talkative. His parents would hit him on the head and curse his voice, calling him in Yiddish "the bell." Despite the unkindness my father experienced at home, he began to excel. He was accepted at Townsend Harris School, where only exceptional boys received a high school education. Moreover, the young Charlie Ozer became a champion soccer player.

My father could have had a career in sports, but instead he chose to become a rabbi. It was at a university dance that he met my mother and later married her.

When my father was writing his doctoral dissertation in Hebrew literature, my practical mother typed the notes he had written on napkins and scraps of paper. I often wonder what my father would have done had he not had my mother to deal with all his practical needs. He was simply poor at attending to routine details. My mother, on the other hand, was superbly organized. My parents were the opposite extremes of the Asperger's tendency to be very weak, or very strong, in their executive function. I was initially like my father; however, with work experience and increasing maturity I began to absorb my mother's ability to organize all my affairs. In retirement, I even organize my wardrobe based on which outfits go with the accessories I plan to wear.

The doctorate led to my father's attaining a position at Brooklyn College, where he was ultimately promoted to Associate Professor and taught until he died. His students adored him. After his death they wrote letters of appreciation to my mother, expressing their love for my father. Those letters filled an entire trunk.

One of my father's obsessions was that he was unworthy of the professorship because he had not published. The college considered sufficient his work as a rabbi, which brought him international recognition —especially when he appointed the first woman cantor in U.S. history. Still, it ate at my father that he was not publishing. He would often tell me, "I want you to write."

My father was plagued with periodic depressions. One episode, prior to my birth, was so severe that he had to be hospitalized. When he left the hospital, my father told the psychiatrist, "I will never be back." Indeed, my father weathered the storms of depression without even resorting to medication. I am sure that my father's incredible sense of humor saved him from succumbing to his depression. Like my father, I suffer from depression, which has almost ceased in the past few years. Also, like my father, my sense of humor always prevents me from taking myself too seriously.

Further Asperger's traits began to surface in my father when he was first hired as a rabbi. He had difficulties with the temple's "powers that be." He would become obsessed with some issue, such as a cantor who seemed to be accorded better benefits. Thus, his career at the respective temple would end.

Finally, in 1952 my father found a position at the newly formed Temple Avodah in Oceanside, Long Island. He had been specially recruited to serve in the first Reform Temple in that village. Owing to my parents' dedicated fundraising, the congregation was able to move from a firehouse to a beautiful building. Throughout his years at the temple my father was a beloved rabbi and teacher. Avodah is Hebrew for work, and work was what my father ceaselessly did there. He also made trips to Israel on his summer vacation, where he became widely known for his knowledge of Hebrew literature and language. My father presided over the temple from 1953 until his death in 1962. In fact, he died on the very day his life tenure at Temple Avodah went into effect.

Dealing with a disabled child was a hardship on my father. He was in many ways a child, needing my mother's constant attention. I represented competition for her attention. As I grew older and required less of my mother's care, my father and I became close—especially in the few years before he died.

During the years in which I was dreaming of a singing career my father was my biggest fan. I will never forget the day he took me to audition for *The Sound of Music*. I stood backstage trembling, certain I was not good enough. My father whispered beautiful words of love and encouragement. After I sang two songs, I heard a voice from the darkened theater: "Honey, don't be shy. You have what it takes." That man who had spoken to me was none other than THE Richard Rogers. My father and I celebrated afterwards with a lovely dinner. We were notified some weeks later that I was on the Preferred List for the musical.

In June 1961, when my father was 48 years old, he was diagnosed with leukemia. His prognosis was three years, but he died one year and three months later. He would speak of future trips, of dinners at fine restaurants, but never of his fate. "I'll get well, you'll see," he would tell me. Then he would make a funny little leap into the air with quivering legs, imitating the famous Russian ballet dancer Nijinsky.

After a hospitalization in December 1961, to control the "blast" of white cells and to give him blood transfusions, my father returned to his teaching and to his congregation. He never forgot any obligation. This quality is typical of many people with Asperger's Syndrome. Just home from the hospital, my father visited a family and asked the little girl what she most wanted. "A doll in a yellow dress," the child replied. My father went to every toy store until he found a doll in a yellow dress.

My father was also selfless. My mother had been pursuing a graduate degree in education and my father insisted that she go to classes even when he lay in the hospital. Dissatisfied with classroom teaching, my mother had decided on special education so that she could teach individual children. My father believed that my mother would be a great teacher, and his faith in her was vindicated.

In the last weeks of his life my father's closest friends from the congregation and Brooklyn College came to the hospital to comfort him, but instead he comforted them. When one of his temple pupils had his *bar mitzvah*, the boy insisted on visiting my father in the hospital where my father blessed him.

During one of my visits at the hospital, my father asked me to sing the Puccini aria "O Mio Babbino Caro" (Oh, my beloved daddy). At the end of the song he wept and said longingly, "I want to see her on the stage." Although I never had a full-time singing career, I did perform over many years some successful and well-paying cabaret programs. I know my father would have been proud of me.

On September 1, 1962 my mother brought me to the hospital where my father lay dying. When he saw me, my father said hoarsely, "I love you, I love you, I love you." I sobbed, "but does he know that I love him?" He nodded and smiled. Then my mother asked me to leave her alone with him. As she was whispering to him fragments of

loving memories, he suddenly rose from the bed with this arms extended upward and called out, "God!" Then he was gone.

At the funeral three rabbis officiated. In his temple, so full that people were standing, women fainted and men wept aloud. The rabbi who gave the eulogy said, "the sun has set while it is yet day." He depicted my father's life with the words, "his was a cup of love."

When they lowered the coffin into the ground, from somewhere in the distance three bells rang. Each bell seemed to sing, "he lives, he lives, he lives."

On my father's tombstone my mother had arranged to have inscribed the words which were the essence of the man she loved: "Noble spirit sweet and strong, wild heart full of dreams." When the musical *Man of La Mancha* played on Broadway, my mother gave me a ticket to see it while I was home on vacation. She said I would find that my father was very much like Don Quixote. He dreamed "the impossible dream" for himself and, even more, for his child. As I write this section of my biography, I hear the record playing "The Impossible Dream."

To dream the impossible dream.

To fight the unbeatable foe.

To bear with unbearable sorrow.

To run where the brave dare not go.

Writing this tribute to my father, I feel keenly the approach of the anniversary of his death: September 1st. It has been 48 years, but I still miss him. I was unable to return to a temple for 40 years because it hurt so much. Now I belong to a temple, and I believe that my father knows. I feel him watching over me. I know that his love has protected me during the most trying times. I see him standing in his long white robes on the Jewish High Holy Days. I can hear his voice the day of his last sermon, when he struggled to finish the service and then staggered to his study.

I am comforted that I carry with me the best of my father. He could teach a language after studying it for a few weeks. So could I, when I tutored Hebrew in Israel. He could remember the day on which any date fell. So can I. These gifts are savant-like and occur quite frequently in people with Asperger's Syndrome or with the Shadow Syndrome of Asperger's. Whatever typically Asperger's obsessive qualities my father had, he had the integrity and decency, which are also found in people with Asperger's Syndrome. His tact and diplomacy are not typical for Asperger's Syndrome; however, these virtues can be developed. I had my father as a living example of sensitivity to others.

Had my father lived longer, I am sure that his gentle persuasion would have resulted in my pursuing a Ph.D. in comparative literature. Then I would have probably trod the primrose path to *academe* and to outward success. Instead I went from music to medical translation, to German, literature, to law, and to psychology. Yet, I believe that my father would be –and is – proud of me.

My Mother

Although my mother is very different from my father, she shared with him some qualities of a person with Asperger's Syndrome such as an obsessive need to do what she had promised. Like my father, my mother always had a sense of duty. The sense of duty is also a virtue of many people with Asperger's. Where she was completely different from my tactful father was in her bluntness. She never learned to modify it despite the negative feedback she received about her remarks. That bluntness is also common among people with Asperger's.

My relationship with my mother was often stormy, and it took me many years to appreciate the fact that her hard-nosed way of looking at me had saved me from becoming hopelessly retarded. My mother sacrificed her potential for a career, which should have been medicine. Instead, she built her life around my father and me. I now understand how she could have felt some resentment towards me for standing in the way of her personal fulfillment.

In my adolescence I dreamed of being a famous singer, but after she had seen me audition for the All-State Chorus, my mother said, "you are not good enough. Don't major in music at college." I threw a screaming tantrum when we came home, convinced that my mother was my enemy. My father comforted me as I lay on the floor sobbing.

Ultimately my mother did allow me to major in voice and theater. After my graduation from Indiana University, she gave me the financial and emotional support to go to Munich, Germany to pursue my chosen career. I have come to the insight that if my mother had not supported me in my goal, I would have spent the rest of my life thinking I could have "made it," and resenting her for standing in the way of the fulfillment of my dream.

As it turned out, I soon realized during the course of my vocal training in Munich that I had to have a secure profession. I therefore studied toward the equivalent of a U.S. Master's degree in medical translation and became a translator for the Max Planck Institute for Psychiatric Research. I also taught English and translation methods. Teaching became a source of joy to me, even greater than singing. My new goal was to become a professor of German.

Although my mother and I often had intense conflicts, I will always acknowledge that she was, in her way, as amazing as my father. When she was 50, she had a severe stroke in the summer cottage she was renting with her gentleman friend Larry. This man, who married my mother a year later, acted quickly and procured for my mother oxygen from the landlord. Had he not shown such presence of mind, my mother might have become a vegetable. Instead, she fought to learn to walk, to speak, and to write again. Then she became one of the pioneering teachers in remedial reading. My mother often said that it was her stroke and the rehabilitation, which came afterward, that made her teaching career possible

When I returned home from Israel, I was unable to find a teaching job. I therefore took a position as a translator for an international publishing company. Although I

did well at work and found an apartment and friends, I began to yearn for an outlet for my intellectual and creative abilities.

My mother commiserated with me. One night she came to my apartment and said, "I have a wonderful idea. I will pay your tuition so that you can take a doctoral degree in German literature. Even if you never find a job, it will be good therapy." I was thrilled, and my dream of becoming a professor was revived. As she was about to leave, my mother drew out a crumpled piece of paper and gave it to me. It was a poem by Olivia Hale entitled "Flowerings." My mother recited the second verse by heart:

The way of all fulfillment goes

Through darkness to achieve the light.

The root whose daughter is the rose

Was nourished in the utter night.

My mother told me softly, "you have not had the success that you dreamed of, but you have something better. You have been privileged to triumph." It was at that moment that I knew my mother really loved and appreciated me. I was accepted into the graduate program of the German Department of New York University, and thus my path towards the doctorate began.

The doctorate was not likely to lead to a tenure-track position in German because the language teaching profession at the college level had "dried up." Nevertheless, I believed that my native-level German and broad use of the language would make me an exception when it came to competing for a college teaching job. Once I was awarded my doctorate with honors, I could obtain only adjunct positions.

My mother, obsessive about my lack of fulfillment, thought constantly about what should be done about me. Larry, who had a law degree, suggested that I study law. My mother proposed that I first take a certification as a paralegal. I took her advice and discovered that I loved civil rights law. When I told my mother I wanted to go to law school, she agreed to the plan and supported me completely through law school.

After law school, from which I was graduated with honors, came three years during which my job search was a struggle. I did manage to find part-time work doing legal research, but the pay was very low. Still, my mother supported me financially and emotionally. She would bombard me frantically with suggestions and even call law firms, pretending to be me in order to see if I could be hired. I would yell at her for interfering. In retrospect, I know that my mother's constant calls and interfering were an indication of her love and concern for me.

Ultimately, in 1999, I found a fulfilling legal position, which utilized both my law school education and my teaching experience. However, I soon began to need more intellectual stimulation. I was doing extremely well on the job, and my Assistant suggested that I go to John Jay College of Criminal Justice and study towards a Master's in forensic psychology. I took his advice and excelled at my studies.

In July of 2000 Larry died. My mother discovered after his death that he had taken money that belonged to her and given it to a former mistress of his. My mother was never the same after that. She and Larry had not been getting along after they were both retired, but this blow proved the beginning of my mother's decline.

Within two years my mother's memory was deteriorating. People who knew her warned me of the decline. I begged my mother to attend a course to improve her cognition, but she reacted in fury. This once-brilliant woman could not face what was happening to her.

A year later my mother needed 24/7 care. I could never put her in a home. To this day, she is surrounded by loving caregivers. I visit her regularly. Until 2009 she would thrill to my calls and ask, "how are you, darling?" However, by 2009 she could scarcely speak. Still, she holds my hands tightly. I ask her, "Mom, do you know I love you?" She smiles and says, "yeah."

As with my father, I carry the best of my mother with me. My mother never failed to meet her commitments. Even when I knew that I would never earn my living with my psychology degree due to my increasing debility, I saw it to the end and obtained the M.A. in February 2008.

My mother truly cared about others and even brought several couples together. I have also brought couples together and helped friends find jobs. As annoying as she could be, I know that my mother acted out of love for me. I, too, was far from an easy daughter. She has forgiven me for being often harsh and unloving; I have forgiven her for her hurtful bluntness and incessant interfering in my life.

I believe that had my parents known of Asperger's Syndrome, they would have understood me, and themselves, better. I have lived with the full-fledged disorder, but they both suffered with shadow syndromes of AS. Thus, the lives of the three of us were united, forming a strange and inextricable trilogy.

The next section of this book is the most challenging because it forces me to confront the demons of my childhood. Those demons were ostracism, mental and physical abuse by my peers, and the effects of the mistreatment, which linger even today.

## Lonely Child: Ostracism, Mental and Physical Abuse in Childhood and Adolescence

Lonely child, you come upon a forest deep and vast.

Birds sing softly of sorrows of the past.

Gnarled trees are bent with grief of old.

The wind is sobbing with agony untold.

This is one of the verses of a poem entitled "Lonely Child," which I wrote when I was sixteen years old. During my early childhood other children would not play with me

because I could not run without falling. Nor could I ride a bicycle. The only child who would play with me lived next door. Her name was Louise. She and her parents moved away after a few years. I was later told that Louise had epilepsy, and that children on the block would beat her and kick her when she lay in a seizure. I never forgot that horrible account. Decades later I thought of Louise when I did a study of epilepsy in literature.

When I was in fifth grade, the torment began. My parents had moved to Oceanside, Long Island and I was literally "the new kid on the block." The teacher was an extremely unattractive woman who saw in me a lightning rod. The children would not mock her if they had me to ridicule. Thus, the teacher told the class that I had been at a "special school" before moving to Oceanside. This was true only because my parents both worked, and the private school I attended kept the children until five.

When I was in the school bus, the girls would kick me as I walked to my seat. I heard the whispers, "freak, creep." In sixth grade I fortunately had a new teacher who put a stop to the children's abuse of me. I will never forget that fine man whose name was Mr. James Boyle. Once I was in junior high school, the blatant cruelty ended. I was simply ignored.

The year I entered high school the taunts started again. I was able to walk both ways and avoid the horror of the bus rides. Before walking home, I would hide behind the trees so that the contemptuous teenagers would not see me.

For middle class Jewish children summer camp was a big treat. My parents believed that the opportunity to engage in sports would be salutary for me. Unfortunately, that is not what transpired. Rather, the children would ridicule me and fight to avoid having "the creep" (me, of course) on their team. Children with Asperger's Syndrome tend to be clumsy and awkward, but in my case I lagged behind in physical development, ostensibly due to my thyroid condition. When my ineptness caused the girls to lose the game, they would wait until the counselors were out of the bunk and then pile on top of me, beating and even biting me.

When I was fourteen, my parents found a new camp. There I became the object of envy as well as scorn. I was very pretty, and my singing ability had become apparent. The older girls were even more merciless than the younger ones with whom I had had to contend at the prior camp. Ironically, the ringleader was Joan, the daughter of the camp's owner. On my last night at that camp a group of the girls held me down while one very repulsive girl bit me in the neck, leaving me with a "hickey." I must admit that I did something to provoke Joan. I told her I believed she was jealous of her mother. My comment was intended to be helpful to her. However, my Asperger's bluntness and extreme social awkwardness caused Joan to hate me. This was because my remark had been right on target. That summer was my last camp experience. Being bullied and humiliated is typical for children with Asperger's. It is an experience we all seem to share.

Even more traumatic than summer camp were my experiences with my cousin Judy. She was healthy, pretty, and smart; and she looked down on me. When my mother and father were visiting with her parents, Al and Rose, I was relegated to Judy's bedroom where we were to play games with her younger sister Debbie, who was never cruel to me. Judy repeatedly told me, "you are stupid."

I also had the misfortune of going to the same dancing school that Judy and her friend Maida attended. After the annual recital, I ran up to Judy and Maida and asked, "was I good?" The two girls smirked. Judy said, "you forgot to go off stage. You ruined the dance." This was not even true, but I was devastated. On the way home in the car, I hung out the window screaming, "I hate Judy and Maida. I hope they die!" My father was appalled, but my mother whispered, "let her scream, Charlie, this may save her from far worse." Some years later Maida died of colitis, and I danced with joy. My mother did not scold me for that; she understood.

Many years later Judy and her husband (both professors by then) told my mother that they planned to have a child because "people as superior as we are have an obligation to put a child into the world." The child they had was, both physically and mentally, profoundly disabled. Judy and her parents wanted to institutionalize the baby, but Judy's husband refused to do this. Irony of ironies, Judy called my mother frequently with questions on how she had raised a disabled child, namely me! I would have forgiven Judy had she even once expressed regret for how she had treated me when we were children. At least, I stopped hating her.

My mother showed enormous insight and wisdom in allowing me to vent when children ridiculed me. She had not yet become a grade school teacher, but she was well-versed in psychology and understood the danger of repressed rage. My mother even encouraged me to curse my young persecutors. Now, when I read or see on the news a story such as the Columbine murders, I often wonder why I never became violent. It was surely in large part because I had a home where neither weapons nor violence had any place. Moreover, both my parents set an example of humane conduct. My mother's amazing understanding of my need to express my rage also figured in the equation. Over the years I have, on occasion, been verbally violent, screaming, "I hope you die" at someone who has severely mistreated me. However, it has never even occurred to me to physically assault anyone.

## High School and the Stage

Gold and silver sound of song a comfort is to me.

When the days seem dark and long you set the sadness free.

I wrote the poem "Song" to express the healing effect of singing. When I was a junior in High School, a world opened up to me. I starred as Julie Jordan in *Carousel*. The director, Miss Williams, had an aversion to me, which made me even more clumsy than I normally was. She tried to replace me due to my inability to handle stage directions, but I threatened to kill myself and thus retained the role. Miss Williams became more

gentle, and my performance was a resounding success. Suddenly I was no longer the "creep," but a talented singer who could mimic major stars such as Shirley Jones and Julie Andrews. In my senior year I had the role of Lily in a scene from *Carnival*. Again, I had great success as the vulnerable waif. My parents were encouraged, and even my mother began to support my goal of becoming a singer.

When I was up on the stage, all the fear and sadness vanished. I was no longer a reject but a star. Contrary to the common belief that people with Asperger's do not do well in public speaking or performing, we are often very gifted for such work. The communication issues people on the autism spectrum have are usually in regard to one-on-one interaction.

The joy I experienced in high school was not pure. During those two years I came to realize that I am a lesbian. My English teacher was my idol. I was obsessed with her until my graduation. Just before graduation I wrote her a letter, begging her to "care for me a little." The result was a call to my mother by the guidance counselor who warned my mother of my "homosexual tendencies." My mother was not convinced and dismissed the crush as a normal stage in adolescence.

#### Romantic Obsessions: Tears of Blood

One of the major aspects of Asperger's Syndrome is obsessions with subjects and with people. Being obsessed with a hopeless love is not uncommon. Sadly, there have been incidents of "stalking," which rarely entail a threat of violence. However, sending gifts and letters, as well as appearing at places where the love object frequents, may result in complaints against the adoring male or female. In some instances police intervention is the outcome.

Although I flourished in my freshman year at Indiana University, in my sophomore year a new obsession took hold of me. I met Nicki, a dark-haired girl with a boyish demeanor and a steely determination to succeed as an opera singer. One evening she sang for me in a practice room and told me that she was "homosexual." I was frightened and denied such tendencies in myself, despite my past crush on my English teacher. Within a few months Nicki began a relationship with an older girl who had been a good friend to me when I first entered college. Then the unexpected occurred: I fell in love with Nicki and was obsessed with her for over two years. She rejected me on repeated occasions, saying, "you are not stable enough for a relationship like this." The pain I felt over Nicki was eased by a book I was writing about coming to terms with my lesbianism. My friends would sit in my room for readings from the book. Those readings changed quite a few preconceptions about lesbian love.

In one passage of the book I described a scene in which I ran after Nicki during a storm, sobbing out my love for her.

The tears streamed down my face

And they were tears of blood. Tears of blood freezing in the icy wind For a love that could never be.

Despite my anguish over Nicki, my years at Indiana University were filled with scholastic success and the experience of having many good friends for the first time in my life. I also loved the college town of Bloomington with its river and forests. For many years after my graduation, whenever I met someone from Indiana, I took that person to dinner as a token of my gratitude.

After graduation from college, I lived in Munich, Germany and attended school to become a medical translator. Not surprisingly, I became obsessed with one of my teachers, a Miss Preiss. She was a lesbian, but unavailable to me because she lived with a lover. I adored her from afar and, again, found release in writing. This time I wrote in German. Sitting in a restaurant, I penned feverishly thewords: "Gesegnete Schoenheit, solche Liebe kannte ich vorher nie." (Blessed beauty, such love I've never known before.") I read the poem aloud and people gasped. They exclaimed that this was really German despite the fact that at that point I could hardly speak the language. The teacher ultimately invited me to her apartment where I confessed my love—right in the presence of her companion. The teacher rebuffed me as both a lover and a friend, and I was disconsolate. Once I had completed my translation studies and left the school, I began to forget about the woman.

When I was living in the United States and studying towards my doctorate I became obsessed with a stage actress named Joanna Lear. Yet again, I loved from afar. My lesbian friends called me a troubadour because I wrote a poem and a story about her. One verse from the poem "Golden Goddess" epitomizes my love.

You to me did heaven send
My mother, sister, daughter, friend.
I pray to see your luminous face.
To worship your majestic grace.

The story I wrote to ease my suffering was called *The Wager*. The tragic heroine Liane (based on myself) meets the goddesses Venus and Diana in a lesbian bar. Venus bets Diana that there is one woman who would die for one year of a great love. Indeed, Liane declares herself willing to die for such a love. Liane has loved an opera singer from afar. The two meet and have that one year of a great love. At the end, the goddesses find out that Liane had a rheumatic heart and would have probably died young in any case. In the first version of my story Liane dies. In the second version she lives, but only to be a platonic friend of the opera singer's and her husband's.

The people who read *The Wager* were deeply moved and encouraged me to submit it for publication. I could not bring myself to do it because I finally got to know the

actress through our membership in a particular organization. I supported her career, coming to see her in several plays. She promised to attend one of my concerts, but she did not come. I never heard from her again. I was suicidal, but my creativity and the obligation to write my doctoral dissertation saved me.

By now it must be apparent to the reader that I was a troubadour in every unrequited love I ever experienced. In lieu of consummated loves, poems and stories arose. Although I believe that reciprocal love should remain the governing principle, I also believe that this ethereal, troubadour love is a viable alternative for a person with Asperger's like me.

I consider myself a lesbian, but I have been attracted to a few men in my life. One could say that I have "latent heterosexual tendencies." One of the men was a professor of mine in law school. I never revealed my feelings to him and simply loved him from afar, as I had done with my female idols. Again, my creativity came to my rescue

I wrote a short play, which I sent to the producer of the television show *Touched by an Angel*. I was informed that unsolicited manuscripts would not be reviewed. Then, about a year later, there was an episode on that series that was clearly based upon my play. My plot involved a music professor who is separated from his opera singer wife and falls in love with a beautiful student named Ilana (which was my cabaret name). The professor composes the music for an opera and Ilana writes the lyrics. In a short time Ilana is dying of a rheumatic heart and the angels Tess and Monica bring her to the home of the professor and his wife who have reconciled. I note that during my obsessions I used to wish I could die young of a rheumatic heart.

At the end of my manuscript, the professor is playing the piano while his wife sings the aria he and Ilana had created together. In *Touched by an Angel* the student is pregnant with the professor's child and dies. The professor and his wife reconcile and agree to raise the baby together. In essence, this was my story, but the "creation" was a baby instead of an opera.

There was another man I adored, but that had a disastrous ending. Edward was supervising a research project I had undertaken. Initially I told him I was a lesbian. He laughed and said, "you will be my greatest challenge. A beautiful lesbian." Slowly I began to feel the adoration I had felt for women in the past. Edward was living with a woman named Rita and they were raising his daughter together.

As usual, I wrote a poem about my love, which had to remain hidden due to Edward's domestic situation. The poem was entitled "Breeches." Two verses express the sentiment contained in the poem.

Dearest, pray tell, how be I sage?

I shall become your gentle page.

My soul now strives and ethos reaches.

As troubadour I don my breeches.

Beloved hide, come forth, comrade.

A girl must masquerade as lad.

True love is made of earth, it seems.

Mine is woven of pale moonbeams.

When I told him that I was amazed at my attraction to him, Edward assured me that he and Rita did not live in the same apartment and were only friends. Edward took me to his apartment where he tenderly caressed me. We had no sex, but my feelings for Edward deepened. I later found out that Edward and Rita did actually live in the same apartment and shared a bed.

One night, a few weeks later, Edward came to my apartment and promised that we would only lie together and caress as we had before. Then, suddenly, Edward forced his penis into my vagina and quickly into my rectum. My bed was full of blood; I had still been a virgin, Edward took a shower and left, telling me it had been "great" for him.

We adult women with Asperger's Syndrome are often like teenagers and are easily deceived by predatory males. Before Edward raped me, I had warnings from others. It was known that this man constantly made advances on women with whom he interacted.

I was numb until weeks later, when I went to a rape crisis center. There the flood-gates gave. Fortunately, I encountered no STD from Edward who had not even used a condom. Nor, thank God, did I contract HIV. Since that night I have never let anyone touch me. That was July 18, 1988. I fell into a severe depression after the rape, but a hugely successful lecture I gave two months later enabled me to surmount that trauma and go on living.

Since my graduation from law school I have not experienced further obsessions. Although I no longer write my troubadour lyrics or stories, my life has become ever so much more serene. I have come to terms with the fact that I cannot love "normally," that is, in a reciprocated fashion. I am sure that this is due to the abuse I suffered in childhood. Still, the consequences could have been far worse. Now I find fulfillment with good friends and feline companions.

With the painful subjects of childhood and later obsessions addressed, I now proceed to cover a major issue for people on the autism spectrum: Sensory Issues.

#### Sensory Issues

It never ceases to amaze me that the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) does not include under Asperger's Syndrome sensory issues, which cause my population so much distress.

One woman I know vomits when she smells meat cooking. Many of us cannot abide a label from a shirt touching their skin. In my childhood I could not stand the taste, or even the smell, of beets. Slimy egg whites repelled me as well. I had a phobia

regarding vomit; the sound of someone regurgitating terrified me. Witnessing someone vomit drove me into a frenzy.

In adulthood I still retain those sensory aversions, but they take second place compared to my new sensory issues. To begin with, my Multiple Sclerosis affects my balance and I find it unbearable to be touched when I am walking on the street. Once I was in a crowded room and I tripped over a man's outstretched foot, falling on my back. Fortunately, I was not injured, although I screamed like a banshee. Since then I avoid all crowds and won't go near crowded areas of the City, such as 42nd Street (East or West), so that no one can knock me down. Clearly, I am terrified of subways. The subway stairs are daunting and I refuse ever to go down an escalator. As a child and a young adult I had no such fears, but in my later years my MS, combined with my Asperger's Syndrome, have become formidable obstacles to leading a full life.

I am also extremely sensitive to several types of noise. One is the base in music. For this reason, I cannot go into many restaurants or attend parties. I am also unable to abide the sound of gum snapping (bubble blowing). The sound of loud, high-pitched female voices on their cell phones, especially when every sentence contains the word "like" at least twice, also irritates me to the point that I remove myself from the proximity of such women.

I should note that my sensory reactions are not solely negative. I love many sounds and fragrances. For example, when I go into a Mrs. Fields store and smell the chocolate chip cookies baking, I tell the sales person that eating the cookies, all warm and gooey, is better than good sex. That usually elicits a howl of laughter. When I pass restaurants, I look at the menus and often drool. One friend of mine told me, "for you, a menu is pornographic literature."

Returning to the subject of my negative sensitivities, my worst reaction is to the sound of a baby screaming or a toddler loudly jabbering. This is especially true if they are in good restaurants, fine stores, or theaters. I have to literally run from the area.

It is interesting to note that in the July 6, 2008 issue of *The New York Times* there was a story about noise complaints in New York City. The greatest number of complaints concerned children's noise. Somehow I doubt that all the person who complained had Asperger's Syndrome.

Next I will discuss the somewhat malicious aspect of my character that Dr. Hans Asperger (after whom our condition is named) deemed to be a symptom of the disorder.

## Malice

Although I was never physically violent, I have always had a rapier wit. I tell people that if someone screws with me, that person will have to look up to look down.

I must confess that my nastiest revenge was on a woman I had adored and who abused me cruelly. I sent her a Valentine's Day card, inside which were two pieces of cat feces. This was my *chef d'oeuvre*, my masterpiece of malice. Otherwise, some of my

less- than- charming behaviors towards people at whom I am very angry include the following:

- Addressing as executive secretaries female executives who have disrespected me;
- Telling the person who won't call me "Doctor Ozer" that he/she must be a member of the JUN Society (Jealous Unaccomplished Nobodies);
- Leaving a voicemail message (using a Russian accent) for aprofessor who had treated me unfairly, informing her that she had been chosen for the job of cleaning the women's toilets in the Yankee Stadium;
- Writing to a supervisor, honestly detailing an employee's incompetence and/or rudeness, and then celebrating when the employee is disciplined.

I think that my readers get the idea. Still, in the overwhelming majority of my regular interactions with people, I am respectful and appreciative. Sometimes I even tell a manager how excellent the employee is. I am often told that more people should complain about poor service and praise competence and respectful conduct.

## **Diagnoses**

In addition to sensory issues and occasionally malicious behavior, persons on the autistic spectrum tend to have co-occurring conditions. The most common are Obsessive-Compulsive Disorder, Major Depression, and Anxiety Disorder. Alcoholism and drug addiction often occur when the person seeks to medicate him/herself. Epilepsy and Tourette's Syndrome, as well as schizophrenia, are diagnosed in the autistic spectrum population more frequently than in the general population.

I now proceed to a discussion of my own co-occurring conditions.

#### Alcoholism

In 1982 I diagnosed myself with alcoholism. My mother supported me in my decision to stop drinking and to join a 12-Step program. I have been sober since October 2, 1982. Now in retirement, I am a member of the Steering Committee of one 12-Step workshop. When I tell my story at a meeting, people come up to me and tell me that I have helped them and that I should be a motivational speaker. I have also chaired meetings over the past 4 years.

#### Depression

Early in 1988, following a protracted depression in 1987 that was seemingly without a trigger, I sought psychiatric help and was diagnosed with Major Depression. The depressive episodes were like tidal waves sweeping over me. When they ended without medication, I was often in a state of euphoria. For that reason, I Initially believed I was bipolar. However, the psychiatrist who diagnosed me rejected this idea because I was too "centered" and responsible. A few months after my official diagnosis, I relapsed due to the rape episode and went on medication. My medication, nortriptylene, has had virtually no side effects and has been effective for over 22 years. Interestingly enough, I almost never feel euphoric since I have been on the tricyclic medication used for people with unipolar (as opposed to bipolar) depression.

When my psychiatrist moved to Maryland, I found a new psychiatrist and continued my talk therapy. In conjunction with medication, this combination has been effective in controlling my depressions. Since 2008 I have been depression free, although I continue to take my medication. That year my psychiatrist told me that I had shown myself to be so stable and resilient over the past years that I no longer needed to be monitored by her. I still go to talk therapy with a social worker named Cal Flachner, who specializes in treating persons with Multiple Sclerosis. Cal is very supportive and helpful to me.

#### Multiple Sclerosis

After years of falling and sensing numbness along with tingling in my legs, I was finally diagnosed with Multiple Sclerosis in 2006. Hip replacement surgery I had undergone in 2003 resulted in increased falls even though I was walking with a cane. My private-care physician told me in 2005 that she suspected I had MS. My MRI showed lesions on my brain.

The next step was a diagnosis by an MS professional. My neurologist, Dr. Joseph Herbert, has a world name. He treats me as a fellow professional who has a say in the treatment. I am in the 15% of MS patients for whom there is no medication; I have Primary Progressive MS which most often strikes people after the age of 40 and impacts mostly on walking. I do have spasms in my legs for which I take neurontin, which is effective and without side effects.

On June 16, 2010 I fell and, for the first time ever, hit my head. Aside from 2 black eyes, I seemed to suffer no ill effects. Then, at 2 a.m. on June 26, 2010, I woke up and saw the room spinning around. I knew what it was from horror stories I had heard from my fellow MS patients. This was vertigo which could cause vomiting and, in severe cases, result in the person being put into a medically-induced coma. To avoid vomiting I lay in bed with my face in the pillow. After four terrifying hours the vertigo ended. During those hellish hours, I feared I might die or suffer a stroke. When I went for my routine appointment with Dr. Herbert, he insisted that I go for an MRI because he feared my fall might have caused a "brain bleed." Thank God, the MRI showed neither

a brain bleed nor a tumor, which I had feared. Instead there was a white flare, which the report indicated might be due to a de-myelinating condition. Since my vertigo attack I have had bouts of anxiety. I fear what lies ahead, but I try to remain hopeful.

For me the hardest part of living with MS has been the excruciating fatigue that, many times, saps all my strength. The bout with vertigo may, or may not, have been due to my MS. Whatever the cause of that episode was, it taught me to cherish every moment that I can lie down without the room spinning. It also taught me to cherish just being alive.

Having MS has meant relinquishing dreams of college teaching and lecturing around the country. Still, an end to dreams is not an end to hope. I have learned to appreciate what I never valued in the past: Being able to take care of myself, waking up in my own bed, instead of in a hospital bed, and walking without falling.

#### Asperger's Syndrome

As I stated at the beginning of this book, it was a psychology textbook that awakened my suspicion that I might have Asperger's Syndrome. I read the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*. Indeed, all the symptoms were there. I was "textbook," as the mental health professionals are prone to say. At last I understood all the difficulties I had had all my life.

I then wrote a letter to Dr. Temple Grandin, the internationally-acclaimed author and professor whose story was included in my psychology textbook. Dr. Grandin called me and told me that she was very sure that I do have Asperger's Syndrome.

Finally, a broadly-educated physician from New Zealand, named Dermot Frengley, was visiting my mother in 2007. He said that he was sure I had Asperger's Syndrome and called me "charmingly eccentric." Dermot added that half the physics professors in New Zealand had Asperger's Syndrome.

Thus, I joined the support group sponsored and led by Michael John Carley, Executive Director of the Global and Regional Asperger Syndrome Support Group (GRASP)

## **Employment: Paid and Volunteer**

First of all, in my 35 years of doing both paid and volunteer work, I have come to view both as "real" work. This is because volunteer efforts may be just as great as paid efforts are, if one is committed to these efforts.

People with Asperger's Syndrome are known to be unemployed or underemployed. I have experienced both. Being unemployed was a nightmare, which, fortunately, never lasted long. I have always been underemployed in the sense that I was grossly underpaid, considering my credentials. Nevertheless, as long as I found the work fulfilling, the title commensurate, and the much-needed prestige present, I was happy. When I was especially pleased with my situation, I often could hardly wait until Monday. In

addition, I would come to work early and stay late. Passionate devotion to work occurs often among people with Asperger's who have commensurate positions.

#### **Teaching**

My first job was ideally suited to my talents and qualifications. I was an instructor of English and translation methods. At Inlingua, the international language school in Munich, I had wonderful rapport with my German students. For the most part they were adults; however, I taught a summer remedial English course to twelve-year-old students. They were unwilling participants until I promised them that in the conversation part of the class they could talk about any subject they wanted (including the anti-baby pill and UFO's). This pleasure would be granted, provided they not tell their parents what we discussed. That agreement transformed these students into members of a mysterious conspiracy, and they could not wait to come to class. Teaching at that school, I was part language specialist, part entertainer, and part psychologist. I coaxed out insecure students and nurtured creativity in all my classes. Amazingly, I discovered that I was a born comedienne who turned learning into fun and laughter. Some of my students became my friends after they left my classes.

My language teaching became a part-time situation in Israel and later in New York. In all my classes I enjoyed fine rapport with the adult students and loved imparting knowledge. I avoided the typical fill-in-the- blank grammar exercises and instead let the students use the new structure (e.g. passive voice) in sentences of their own creation.

When I became an attorney I enjoyed adjunct positions at a local college, and later at the Academy of the New York City Department of Correction.

#### Translating

Even before I had concluded my studies in the translation program and attained the title of Medical Translator, a fellow student introduced me to a psychiatrist at the Max Planck Institute for Psychiatric Research. From 1969 until I left Germany in 1972, I enjoyed the rank of "Exclusive Translator" for the research institute. The top professor there, who was my supervisor, tried to induce me to go to medical school. He claimed that my understanding of complex material was phenomenal. When I said I was not smart enough to go to medical school, I was tested and emerged in the genius category. Still, I was so happy in my teaching that I did not take the advice of the professor.

When I sought employment in New York, I could not find a full-time job doing the medical translation I had so enjoyed. Thus, I accepted a full-time position at a publishing company, where I translated legal and business documents as well as wrote letters in German. Initially I was called a Translator, but later on I was the only person with German language skills. My credentials in German translation and German Literature earned me the title of German Language Specialist. I worked at the publishing company for nearly twenty years and was basically content —although not happy. The secretaries whispered about me, in part because I was eccentric, and in part because they resented my position (professional as opposed to clerical). At that point I knew how to strike back and would make demeaning remarks to the effect that average people always resent those above them.

During my years at the publishing firm a seed was planted for a law career because I experienced constant sexual harassment at the hands of two male executives. I did not know that what they were doing was against the law. The Clarence Thomas confirmation hearings in 1991, with the testimony of Anita Hill, were, therefore, a shocking awakening. That year I discovered that the publishing company was being sold. It was then that my mother and Larry offered to send me to law school.

#### Working in the Legal Profession

In the three years following my graduation from law school I was often unemployed or barely subsisting on part-time legal research assignments. Sometimes I did Court Appearances, which I found a welcome change. In general, the attorneys who supervised my work were appreciative. My goal was to work in the area of disability rights.

Finally, in 1999 I was selected to head the Disability Rights Section of the Equal Employment Opportunity Office in the New York City Department of Correction. My dream had come true: I was working in the field of disability law. The work was challenging and I loved being able to vindicate the rights of disabled employees, even though I often could not secure for them the accommodations they sought. In addition, I reviewed claims of discrimination. I found it especially exciting to go to depositions and to testify in court. Moreover, teaching Disability Discrimination Law at the Department's Academy provided me with enormous gratification. Most of my colleagues were kind. The Deputy Commissioner of EEO was warm and supportive, especially when I broke my hip and was later diagnosed with MS. I remained in this position for nearly eight years until my MS made it extremely difficult to work full time. At age 62 I took early retirement.

## Singing

I must admit that my paid singing career was not substantial. In Munich I had two steady and very low-paying "gigs." One was in a cabaret where I sang chansons and folk music. The other was in a wine house where I sang operetta and opera arias as well as show music. The German audiences were delighted with my ability to sing in many styles and many languages (about 14, including Hungarian and Polish). I was frequently called "the little girl with the big voice." The wonderful and loving female owner of the Cabaret was named Gisela. She and her husband were like adopted parents to me. They introduced me to an agent who wanted me to go to Israel and come back to Germany as an "Israeli" singer. (At that time the reparations desire in Germany was

quite strong.) I declined, knowing that doing this would be misrepresentation and even fraud. In addition to my regular singing "gigs," I sang a few concerts in Switzerland.

Back in the United States, it took me several years to find myself as a concert and cabaret singer. From 1982 to 1993 I performed twice a year, writing my own one-woman shows and singing in multiple voices and languages. My audiences especially relished my near-perfect imitations of Julie Andrews, Dolly Parton, Marlene Dietrich, Edith Piaf, and Judy Garland. Soon I had a subscription audience called "the Circle of Support for the Singing Scholar." I was working full time and completing my doctorate in German Literature while preparing for these shows. My audience members paid me annually from \$15.00 up to\$50.00, with an occasional contribution of \$100.00. I rented a space called 22 Below for my shows. The little basement room was much like a bohemian nightclub in Paris.

While completing law school and then working as an attorney, I could no longer keep up my paid singing. Thus, I began to do benefits for the homeless and for innercity children's summer camp experience. Not being paid did not detract from the joy I experienced from these performances.

#### Volunteer Work

Although my unpaid work began with singing benefits, it also encompassed legal work. Doing the research in a criminal defense case for a client with Lupus was a reward unto itself when my supervisor and I succeeded in getting the indictment dismissed in the interest of justice. My internship at the Equal Employment Opportunity Commission (EEOC) was so enriching that I cried when it was over. The supervising attorney, as well as one of the top administrators, valued me and gave me superb references, which later helped me obtain my position with the Department of Correction.

My career as a scholar never resulted in monetary gain; however, the prestige I experienced when my work was published, both nationally and internationally, surpassed any remuneration I might have been received.

The most rewarding scholarly project in which I was engaged dealt with the portrayals of epilepsy in literature from the Bible to the present. My work became known even before it was published. I received invitations to lead workshops and to be a keynote speaker in a German conference on epilepsy. I could not accept the invitation from Germany due to my law school obligations, but I discovered that my research had inspired that German neurology institute to create an archive on literary works regarding epilepsy. In 1990 my article was accepted for publication by the major journal *Epilepsia*. In the fall of 1991 the article appeared in print. It was one of the most triumphant moments of my life. Not being paid did not detract from the joy.

Leading support groups proved extremely gratifying to me. From 1989 to 1996 I was counselor to the Newcomers at the National Mood Disorders Support Group. During the same time period I also led a support group for persons with alternative

life styles. Lesbians, Gays, Bisexuals, and Transgender persons attended this group. In both groups I received praise for my "empathy." Despite not knowing what the group members were thinking, my own painful experiences had imbued me with the capacity to understand their pain. It was my work with these two groups that later inspired me to study towards a Master's in psychology.

Acting as a consultant on discrimination cases has been rewarding even though I have not received remuneration. Shortly after I retired, I volunteered as a consultant to a young man who had been terminated from a residency at an Ohio hospital. The discharge was due allegedly to his Asperger's Syndrome. I reviewed all the documentation and gave the plaintiff my evaluation of his lawyer's and the defendant hospital's positions. Sadly, the case was defeated on a motion before it could go to trial. The consulting work was challenging, but I would not want to do such work on a regular basis.

Although my paid teaching jobs gave me great fulfillment, I also derived great pleasure in teaching after my retirement. I was part of the Prejudice Reduction Program of a retired seniors organization. We went into grade schools and led groups of 4th graders in discussing bias against gender, race and disability. The project lost its funding in 2008, but I will never forget how receptive and delightful those children were.

I no longer have the stamina to teach with any regularity, but I still lecture at various disability groups and find it most rewarding despite not being paid for the presentations. I especially enjoy speaking before the GRASP support sessions. Asperger's Syndrome has become my topic of choice when I lecture.

Finally, my volunteer activities at the East End Temple have been exciting and have yielded a significant spiritual reward. In 2007 I sang a benefit concert in my multiple voices and languages. The audience was wonderfully receptive, and my performance resulted in enough money to purchase a breastplate for our new *torah*. In 2008 I advocated for the EET Diversity Project to be launched. With the collaboration of two wonderful women I managed to put together a round table consisting of representatives of the GLBT community, the multicultural community, and the disability community. I represented the disability community. The program went very well and paved the way for the 2010 Disability Awareness Day—the first such event ever to be held at our temple. There were four speakers, including myself. My friend Ellen Lamonoff co-chaired the event with me. The attendance was excellent and the response strong.

Concluding my discussion of volunteer work, I emphasize again that it is the feeling of significance that, in my opinion, surpasses any monetary reward. We who are on the autistic spectrum tend to evince a profound dedication to the work we do, and that dedication is usually not contingent on being paid.

While my past and present work has been a source of consolation during very difficult periods in my life, it is also compassionate and supportive people, who have enabled me to persevere. I now turn to these wellsprings of consolation.

## Wellsprings of Consolation

I begin with Roger Goren, who is the brother I never had. In crisis moments, he is like a father to me. Despite his modest demeanor, Roger is a major figure in the insurance world. His father had insured my parents. Now Roger takes care of my mother's finances and mine. I can honestly say that he is one of the anchors that keep me afloat in bad times. To Roger I am a genius who has a hard time handling stress. Yet, he is there applauding me when I rise to the occasion. When Roger underwent a cardiac operation, I lived in constant terror until I knew he was back to his old self. As my mother is becoming increasingly frail, I am growing more practical with every month. Roger makes me believe in myself. His friendship is the greatest privilege to me.

Anna Trojnar is my mother's caregiver and also a wellspring of great consolation. Like Roger, she is an anchor in the storm. I consider her my adopted sister. Anna is beginning to help me with the heaviest cleaning that I can no longer manage. The mere thought of shopping for a new sofa bed renders me nauseas. I can no longer walk around in the crowds in midtown. Anna attends to it. She is always there to comfort me when I am frightened or depressed.

Both Roger and Anna have also adored my cats. My beautiful young feline Maggie is ecstatic whenever Roger or Anna comes to see me. Indeed, with my father deceased and my mother demented, Roger and Anna are my family. We are united in a bond even more powerful than blood. That bond is love freely given.

Lillian Burg had been a wellspring of consolation from the time my father died. Lillian and her husband Lou were my father's students in Hebrew school when they were children. Years later my father brought them together at Brooklyn College and officiated at their wedding. Lil always said she saw my father in me. In 2005 Lil died. She was in her eighties, but full of verve and love of life. She and Lou had lived in Los Angeles since I was in college. I knew that if I ever needed Lil, she would have been there for me.

Kim Rich Norton has been a wellspring of consolation for over twenty years. She and I became friends in 1988 when she became my accompanist. Her creativity, both in composing music and writing the lyrics, is on a genius level. Still, Kim is devoid of the vanity and selfish ambition, which drive many artists to outward success. When I was in the throes of anguish over a romantic rejection or abuse at work, Kim's calm words soothed me. She was also there for me when I was raped. Now she and her husband Shawn live in New Jersey. Despite Kim's more than 20 years of loyalty to a major financial organization, she lost her job when her department was eliminated. Kim's excellence in research and writing needs to be utilized, but even in unemployment she is never bitter. When Kim was commissioned to write the lyrics for an opera, which was performed in Finland, I rejoiced with her. She has always rejoiced in my every accomplishment. Recently I was thrilled to hear that Kim has some paid part-time teaching work.

Although Bill Arnold now lives in California, he was a wellspring of consolation during the time he was my neighbor in Gramercy Park. When I broke my hip, it was Bill who came to see me in the hospital and brought me clothes and other necessities. He also took care of Portia, who was my precious feline companion at the time. Bill had the most beautiful Yellow Labrador Retriever named Graham. When we went out to eat, Graham was under the table caressing my feet. Bill was working towards his doctorate in education while I was completing my Master's in forensic psychology. We would commiserate with each other during the hardships of academic pursuits. We both achieved our goals and, despite being 3,000 miles apart, we remain spiritually close. Like me, Bill has battled depression and triumphed.

Carolyn Berry was a friend to me from the moment I first applied to the Department of Correction. She certified me as a candidate and told me, "you go to the head of the class." Because Carolyn has two Master's degrees, she appreciates the value of higher education. She often calls me "Dr., Dr. Master, Master, Master." Since 1999 Carolyn has cheered me on every step of the way.

Dalia Ortega, a colleague of mine at the EEO Office, was a wellspring of consolation. When I was ridiculed and maligned by two openly anti-Semitic African-American women in the office, Dalia comforted me, saying that the women were jealous of my status and salary. In all fairness, the other African Americans with whom I worked were very kind. Dalia respected my value to the office and always assured me of it. Although she does not have a college degree, I always tell Dalia that I consider her to be brilliant and insightful into the motives of others. We are regularly in touch. Although I do not miss working, I do miss Dalia, and she always tells me that she misses me.

Roberta Tayer has been a wellspring of consolation since we worked together in the Prejudice Reduction Program. This woman shares my love of cats and even calls her cats "domestic partners" (which she got from me). When my cat Portia died, Roberta was there for me in a way that few people could be.

Ellen Lamonoff, my new friend from temple, is indeed a wellspring of consolation. When she co-chaired with me the temple's Disability Awareness Day, I had the chance to see a great human being at work. Ellen is Director of Nursing Services at a large facility for adults with developmental disabilities. She also holds a Master's degree in Nursing. Ellen won a 2010 award granted by a major Jewish organization to two professionals who exemplify the highest standards of service in the area of special needs.

I will never forget the day I took Ellen out to lunch and learned that her dog had recently been put to sleep. I invited Ellen to meet my cat Maggie. The moment Ellen walked into my apartment, Maggie began to nuzzle her gently. Ellen was amazed. So was I, since Maggie had never shown any other visitor that degree of affection. I believe that Maggie sensed Ellen's loss, and also the goodness that makes Ellen such a wellspring of consolation.

## Cats or Angels Sent by God?

The uncanny power of various animals to draw out autistic children and adults has been the subject of television segments. The authors to whom I will pay tribute in my section on Beacons describe special relationships with animals. Dawn Prince-Hughes was transformed by her relationship with gorillas. Daniel Tammet found love with a cat named Jay. Dr. Temple Grandin had a profound bond with cattle. Finally, William Stillman included the amazing love that has arisen between autistics and animals.

Although I am dedicating this section to the feline companions with whom I have been blessed over the past 38 years, I first want to take a trip down Memory Lane regarding other animals. Despite the fact that cats have captured my heart, I also love dogs, especially Beagles, Yellow Labradors, and Chihuahuas. I frequently stop and talk to the dogs being walked, much to the amusement of their human "owners." Once I told a Labrador that he looked like a Harvard man. The dog jumped up and put his arms around my neck, hugging me. I knew he understood exactly what I was telling him.

While spending a few days with my parents at their rented vacation cottage, I would walk in the woods. I swear to God that all the dogs along the way followed me to my parents' cottage. The amazed owners had to pick the dogs up at our rented summer home. My mother called me a Pied Piper for dogs.

When I was about eleven years old, we had a cat named Calico. My mother could not bear the poor cat and was driving her to the shelter, when Calico jumped out the car window. Several hours later a calico cat appeared in my schoolyard and ran up to me. It was my Calico. This cat had never been at my school. Then how did she know where I was?

I believe with all my heart that dogs and cats living with disabled persons are not animals but angels sent by God to watch over us. With that said, I begin my letters to my precious angels, three who have left this earth, and to Maggie, who is now my enchanting special friend.

Else Lasker-Schueler

Dearest Else,

I named you after a German-Jewish poet. To me, you were poetry. A tuxedo cat, you were so prim and quiet. You were a port in my recurring storms, and you loved me unconditionally. When I saw a lump in your haunch, I immediately took you to the veterinarian. Although I exhausted my savings paying for your surgery and chemotherapy I have no regrets. Despite the treatments, you died at the age of seven and a half years. I called my mother at 2 a.m. and she came to comfort me.

A story I wrote entitled *Else*, the Felicitous Feline captured the essence of you: Loving, accepting, caring for me when I did not care for myself. You were my first Manhattan cat and I will always be grateful to you.

Virginia Woolf (a/k/a Virgie)

My precious Virgie,

It was five days after Else's death that Melvin, a friend of mine from work, brought you to me from a pet store. You were three months old, a tiny tiger-striped calico with green eyes. It was March 1, 1985 when you first graced my apartment. Initially shy, within days you ruled the roost. When I had set out a cake with chocolate icing, you gobbled up the icing. My guests were doubled over with mirth. You stole my lunches out of my purse and rejected cat food in favor of my food.

You were tempestuous and enraged if my concentration was diverted from you even briefly. When I was studying for the New York State Bar Exam, you would grab my wrist and kick and bite me.

Yet, you were so loving. No one has ever loved me as you did. You slept next to me with your arm around my neck and your cheek against mine. When I lay in bed sobbing over a disappointment in love or at work, you wiped away my tears with your paw.

You never ceased to amaze me. When I was practicing scales for a concert, you actually sang the same scale with the vowels "nyau, nyau, nyau, nyau." Once when I was in the bathroom I heard music emanating from my small organ. You were walking on the keys.

You were uncanny in your ability to sense what people were really like. When Edward came to visit (and then to rape) me, you hid from him. You always knew who really loved you. No one could fool you.

You hated it when I went away without you. On one occasion I boarded you when I went to a conference for a few days. When I picked you up and we came home, you would not look at me but climbed to the top of a cabinet and wailed. Finally, you got hungry and came down to eat, tossing your little head, still refusing to look at me. Another time I was gone briefly and came home to find that you had torn up my favorite book after taking it off the shelf.

I immortalized your brilliance in a short story called *The Cat and the Computer*. In this tale, an amazing computer firm was started by you and your gentle tom-friend Leonard, along with various cats named after the illustrious members of the Bloomsbury Circle.

On May 28, 1998, a few months after your thirteenth birthday, you vomited in a corner of the room and collapsed. I brought you into the veterinarian, but it was too late. You had suffered a stroke. They put you to sleep while I wept at home.

In the days before I adopted my next cat I contemplated suicide, but I knew that it would destroy my mother who had supported me through so much.

Portia

PreciousPortia.

I adopted you at the Bide-A-Wee shelter on May 31, 1998. You were a year and a half old and so thin that I could count your bones. Like Virgie, you were a tiger-striped calico. I named you Portia after the heroine of William Shakespeare's *The Merchant* 

of Venice. While Virgie was my literary cat, you were my lawyer cat who passed the bar (actually a tavern, in your carry case on our way to the vet's).

It took us longer to bond, but once we did, it was a strong and serene love. In contrast to Virgie, you were reserved and calm. When I went to California and returned, you greeted me without anger and hugged me.

I will never forget the time I broke my hip and spoke to you over the telephone. My friend and neighbor Bill Arnold was in my apartment to feed you and he brought you to the phone. I sobbed brokenly, "Portia, it's mommy, I miss you so much!" You yowled into the phone. When I came home, you jumped into my arms and hugged me. Doing my exercises was fun because you would lift your leg as I lifted mine. When I went for an MRI and lay exhausted in my bed afterwards, you sat on my chest and kissed my eyes.

The years went by marked by your sweetness. As soon as you heard me at the door, you jumped off the couch and ran to greet me at the door. My beloved Portia, you were my Domestic Partner and equal. I viewed us both as two older women, even though others saw you as an animal.

Suddenly everything changed. At about 2 a.m. on December 19, 2008 you suddenly vomited what looked like a lake of water. I was terrified, but then you were all right the next day. Until March 15, 2009 you had no further such episodes. Then it began again. You vomited this liquid five more times between the 20th and the 28th of March. It stopped suddenly and you seemed fine. April 7th was the last day on which you could eat and walk. You sat on my shoulder and purred into my ear. When I showered, you were next to me on my bench. You slept nuzzled on my back. The next day you did not eat and had difficulty walking.

On April 9th I brought you to Dr. Kuhlman, your beloved veterinarian (whom we called your PETiatrician). He gave you tests and said that your kidneys had failed. It was too late to reverse the condition. I cursed myself for not bringing you to Dr. Kuhlman sooner, but he explained that I had been deceived by your ability to compensate, and consequently to hide your illness. That afternoon you were put to sleep. This time I had the privilege of being present for the end. After you had your shot, Dr. Kuhlman said you were gone. I walked home sobbing, carrying your empty case.

As Else and Virgie were immortalized in stories, so were you. The Conversion of a Cat tells how you decided to convert to Judaism although you were "steeped in New Testament tradition." You became a member of the Felines of the Jewish Faith (FOJEFs) and went on a trip to Israel.

Forgive me, Portia, my beloved friend, for failing to take proper care of you when you always took care of me. I know you realized how much I loved you and always will. We had almost eleven glorious years together, and I will always be grateful to you for that.

Because there was capital improvement going on in and outside my building, I decided to wait until it was over before adopting another cat. After a few weeks I was, yet again, so depressed that I did not want to go on living.

Thus, on May 1st I went to the Bide-A-Wee shelter for the second time in eleven years. There, alone in a cage, I saw a tiny kitten. She was black with just a ruffle of white around her neck and large golden eyes. The attendant let her out and the kitten jumped on my shoulder, as Portia had always done, and began to kiss away my tears. This was the cat with whom I am now living

Maggie

Dear Maggie,

They called you "Gorilla Baby" at the shelter, but I named you after my parents, Margaret Charles. You are called Maggie (named after Maggie the Cat in Tennessee Williams' play *Cat on a Hot Tin Roof*).

We have been together for well over a year and I love you more and more with the passing of time. Whereas I never worried about Else, Virgie, or Portia getting sick and dying, I worry about you all the time. Once you had diarrhea and I brought you right into the veterinarian. You had eaten too much "greenies." You will eat anything: newspaper, salad, cake—and coffee! I have to keep you in your carry case when I eat or I would go hungry. I constantly keep watch over you. Every day at about 3 a.m. you meow and I hold you in my arms and rock you while you purr. Sometimes you sit on my chest and lick my face and my lips. When I close my eyes, I could believe that I am being caressed by a lesbian midget in a mink coat.

Shortly after I adopted you, another story arose in which you hacked into President Obama's e-mail. The story is entitled *Maggie's Revelation*. and the message emerges: Animals who live with disabled persons are angels sent by God. In the story the dogs and cats, with their disabled humans, march on Washington. They demand family member status for animals who nurture the disabled. The animals arise and speak to the crowds. And it comes to pass that the Animal Family Member Act is signed into law

Maggie, you sat at my computer and actually hit the keys. Then you tried to jump into the television set when the Obama family was shown. This was the inspiration for the story.

I tell my friends crazy stories about you, such as your plan for a reality show called "Feline and Fruitcake." The laughter hides the tears beneath the surface. I love you so much that I pray I die before you do. I could not bear another loss of an animal angel.

All my feline angels often kept me from suicide. Thank you, all.

## When All Is Said and Done

Today I sit at my computer, 65 years old, fighting the fatigue of Multiple Sclerosis. Seven years ago the Chair of a prominent Disability Studies program invited me to come for an interview. It appeared that at last I could become a full-time professor. Then came the broken hip and the MS diagnosis. Strangely, I did not turn bitter. My first psychiatrist often referred to "the glass half full or half empty." I could focus on

all my past pain and disappointment, but I choose instead to focus on my triumphs and joys. I have made many poor decisions and taken ill-advised paths. Still, as the Frank Sinatra song "My Way" goes:

Yes, there were times, I'm sure you knew When I bit off more than I could chew. But through it all when there was doubt I ate it up and spit it out.
I faced it all and I stood tall And did it my way.
The record shows I took the blows And did it my way.

My greatest comfort is that, despite my unconventional education and work history, I utilized the gifts God gave me, and I did not allow my disabilities to prevent me from striving. Those of us who have exceptional, even savant abilities, often bear the burden of some form of mental or developmental challenge.

In the short presentation I wrote called *Fragile Genius: Shattered Dreams*, *Silent Screams*, the characters ask the U.S. President to create an agency that trains and places us truly special people.

At present, there are organizations, both in Denmark and in the United States, which both train and place autistic persons. It gives me hope. I no longer scream silently over my shattered dreams. Looking back, I see now that undreamed-of miracles have occurred in my life.

Since I turned 65 I often think of death. I have searched for God in the Bahai and Christian faiths. I often asked how God could give my father leukemia when evil people walked the earth. After reading When Bad Things Happen to Good People by Rabbi Harold Kushner, I have come to agree with the author that God does not control nature's cruel power reflected in the violence of Hurricane Katrina. Nor does God control nature's cruel power in inflicting the fatal diseases borne by children and good people like my father. Like Rabbi Kushner, I believe also that God weeps for us and sends us comfort and strength to go on.

Now I want to be at peace with the world as well as with my fate. I know that at times I am very nasty and vindictive. If I get into Heaven, it will be because God grades on a curve. Recently my friend Kim sent me the words and music to the song "Going Home," based on Dvorak's *New World Symphony*. A second verse was composed in 1922 by William A. Fisher. These lyrics give me strength.

Morning sun lights the way, restless dreams all done. Shadows gone, break of day, life has just begun.

Every tear wiped away, pain and sickness gone. Wide awake, there with Him, peace goes on and on. Going home, going home, I'll be going home. See the light, see the sun. I'm just going home.

Although both my Multiple Sclerosis and my Asperger's Syndrome pose challenges, I am still happy because Asperger's also gave me wings to transform the pain in my life from a prison into poetry. After my vertigo attack ended, I found the strength to write this autobiography. Two lines express my new-found strength.

Tormented night gives way to radiant morn. Man must die that the poet be reborn.

# **Epilogue**

For the readers of this book, I hope that the interdisciplinary approach I took will put Asperger's Syndrome in a light that is both accessible and meaningful. Even if it does not reach a wide spectrum of the public, I believe that it will impact on the consciousness of those who choose to read it. Like people of all types, with or without disabilities, we who are on the autistic spectrum have our foibles which may be annoying or even distressing to many. As you continue with your reading, please be open to entering a terrain that is unfamiliar, yet part of a world we, too, have the right to call home.

I now turn to the accounts of the authors with Asperger's Syndrome who have been my greatest sources of inspiration – my Beacons. I will also allude to the impact, or lack thereof, their works had on the public consciousness.

In this section I do not mean to imply that there are no other authors on the autistic spectrum who have inspired me. I would, for example, recommend to the readers of this book the two biographical works by Donna Williams entitled *Nobody Nowhere* and *Somebody Somewhere*, as well as the article by music critic Tim Page entitled "Parallel Play," which appeared in *The New Yorker*.

# Beacons: Authors with Asperger's Who Inspired Me

# Jesse A. Saperstein

Dark, intense Jesse became my friend in 2009 through our membership in the GRASP Support Group. He was in the process of getting published a book, entitled Atypical, about his life. At one session he read from part of the book. I was already captivated. During the long and weary months of writing my own book, Jesse gave me the support I needed. His courage in revealing himself, "warts and all," imbued me with the strength to write even when my MS made it difficult to sit for hours at a time. Jesse was excited about my approach to Asperger's Syndrome and promised to send my manuscript to his literary agent.

After reading my book, Jesse said that I should write my whole story—for example, about being a lesbian. Now I have taken Jesse's wonderful advice.

Since Jesse was unemployed and struggling, I offered to pay him for his help. I am glad that my relative financial ease enabled me to do this. When I had finished my manuscript, Jesse wrote a letter of praise for my work to his agent, Jeff Herman. In February of 2010. Mr. Herman solicited my manuscript. Jesse and I were filled with hope.

In April 2010 Jesse's book came out in print. I promptly ordered four copies, which I sent to close friends. I read Jesse's book and found it superb, both in content and in style. Upon reading it a second time, I was even more impressed. His use of the English language is pure poetry.

As my own story reveals, I have enjoyed professional success with my scholarship. Now I can honestly say that the success of Jesse's book is more important to me than that of my own. For this reason I was not upset when Jeff Herman e-mailed me a message, saying that my book is not "commercial." Mr. Herman urged me to send my book to an academic publisher and not to bother with getting an agent. I am now re-working my book. I am relieved that Mr. Herman rejected my book rather than Jesse's. Jesse speaks to people everywhere; my book will be far more limited to a potential audience of students, professors, more educated persons with AS, and parents of children with AS. Having discussed my personal relationship with Jesse, I will turn to his book –both unique and powerful.

Atypical Life with Asperger's in 20 1/3 Chapters was reviewed by persons enjoying significant prestige, such as Executive Director of GRASP, Michael John Carley, and professor /author Dr. Temple Grandin. Actress Sigourney Weaver, who portrayed an autistic woman in the film SnowCake, also praised Jesse's book. She has advocated for the Asperger's community members in our quest to be accepted for ourselves.

The Introduction to Jesse's book establishes his "differentness" in the very first paragraph. His mother had just given birth to his sister. Little Jesse discovered the controls to his mother's bed and operated them. He was oblivious to the fact that his mother was only semi-conscious.

Toddler Jesse evinced no interest in imaginative play and avoided socializing and eye contact. These were "autistic-like tendencies," noted a medical professional who evaluated Jesse. However, unlike most autistic children, Jesse was highly verbal and affectionate. Born in 1983, before the Asperger's Syndrome diagnosis was included in the *DSM-IV*, Jesse wrote that his high-functioning autism was a disability so "profoundly mild" that people considered it a character flaw. Jesse poignantly described "quagmires of chronic failure and bitterness that have lasted up to years at a time."

By the time I had finished reading the Introduction, I knew I had found a soul mate in Jesse. Although Jesse's account is completely different from mine, I identify with his story. I know his despair and his triumph. Moreover, Jesse is funny, especially when he erroneously thought that Asperger's is ASS-Burger (slang for a bowel movement).

As I forged ahead with Jesse's book, I encountered even more of the familiar: "Loser, weird, creepy, stupid, annoying." These epithets were in response to both Jesse's, as well as my own, brutal honesty and often- intrusive behavior, which led to brutal rejections. Like Jesse, I could not take a hint when I was not wanted.

I do not wish to digest for my readers Jesse's entire book, but there are parts that I consider spectacular high points well worth citing. Jesse's depiction of his obsession with Christmas greetings had me doubled over laughing. Since I live alone and have no close family, I categorically hate ALL holidays. Jesse had been reading my book during the Christmas season in 2009. Instead of sending me the critique I was awaiting, Jesse inundated me with Christmas messages until I sent him a blistering e-mail expressing how much I hated the lousy holiday season. I ordered him never again to mention the holidays. He finally "got it," and his holiday epistles stopped coming.

In his chapter on empathy, Jesse courageously tackled head-on the alleged lack of this attribute in people with Asperger's. Although throughout his school years Jesse was criticized by teachers for having no consideration for others, he did learn "artificial empathy." This was an art to be refined throughout his adult life. At the conclusion of this chapter, Jesse noted that persons not on the autistic spectrum are unable to understand how he, as an adult, can be so self-conscious and yet lack awareness of other people's pain. As Jesse admitted, there are no clear answers to "the enigma of Asperger's Syndrome." Jesse concluded that people would find "unexpected treasures" if they were open to the redeeming qualities of the AS population. One of these qualities is the AS integrity, so often lacking in the "artificial empathy" our society accepts.

In the chapter on "Psychobabble," Jesse had a brilliant suggestion: The ideal therapist for an AS patient would be an adult with AS who would also be a role model. We who are on the autism spectrum need to be treated by professionals who have real knowledge –as opposed to book knowledge – of our AS. Now that I have attained a graduate degree in psychology, I hope to find opportunities to help young persons on the spectrum. I am perhaps not such a perfect role model, but I could counsel Asperger's youth, and thus spare a younger person with AS some of the anguish I experienced due to my behavior. Jesse is achieving this, even without a degree in psychology.

In the chapter on "summiting the stigma," Jesse related how his service to the HIV/AIDS population at Camp Teens Living with Challenges (TLC) inspired him to walk the Appalachian Trail(the most challenging footpath in the world), in order to raise money for his friend Joey Di Paolo. It was at Camp TLC that Jesse found love and acceptance, where he had expected hatred and rejection. All the money raised by Jesse's walk went to the Joey Di Paolo AIDS Foundation. Jesse, who had no prior hiking experience, finished the hike in seven months.

In Jesse's "Epilogue," which begins with a description of his depression following his triumphant hike, he observed that "true despair comes not only from perpetual failure, but an absence of hope." Jesse found hope when he committed himself to the decision to write a book about his life. A friend of his encouraged Jesse in his plan. After many rejections, Jesse finally found the literary agent to whom he paid a tribute, saying that with her help the "embers of hope reignited."

Jesse does not regret his life of highs and lows. He won't "shirk the opportunity" to help his readers with AS. He does forewarn, however, that his advice and self-help derives from a man who "enjoys farting in public and talks gibberish to his cats."

As far as the impact of Jesse's book on the public consciousness is concerned, Jesse has become a local celebrity in Upstate New York. He gives readings and lectures on his life and his book. I believe that he will become an international celebrity with time and patience. He well deserves such recognition for his brave, exquisite book and for his wise counsel to others with AS. His book defies the stereotypes of our population.

If Jesse encouraged me to include a full autobiography and to obtain his agent to represent my book, Valerie Paradiz encouraged me to begin to write the book.

# Valerie Paradiz

Valerie Paradiz and I first spoke by telephone on May 31, 2008. I had just read her book *Elijah's Cup* and found in her a spiritual soul mate. I had no trouble reaching her. We were both amazed that we had in common a Ph.D. in German Literature. Moreover, Val's son Elijah's first symptoms of autism were seizures. I myself had spent years researching, publishing and lecturing on epilepsy in literature. Val and Elijah lived with a lesbian for a time. I am a lesbian. The subject of Val's doctoral thesis

was the German-Jewish poet Else Lasker-Schueler. My deceased cat was named after the same poet. Finally, Val herself was diagnosed with Asperger's Syndrome. Just as I was.

Val read parts of my book and encouraged me to forge ahead with it. She also interviewed me for an article she was writing for an autism journal. This interview, unfortunately, was not included in Val's article, and both of us were deeply disappointed. Only the fact that I was writing my book was mentioned in the final version of the article.

What moved me most deeply in *Elijah's Cup* was Val's profound love and caring for her son. She showed him respect even when he was a difficult young child, and she never became impatient with his repeated questions of her. Initially believed to be severely autistic, Elijah was later diagnosed with Asperger's Syndrome. The young man even became a comedian. Val's faith in her son's ability to thrive was vindicated.

Val's book on Elijah's life is her great literary contribution to the autism/Asperger world. It is written by a true scholar. Val informed her readers of a list of persons(for example Einstein, Wittgenstein and Warhol) who probably were on the spectrum. From a medical point of view, Val researched the symptoms of AS so thoroughly that she was able to diagnose both her father and her paternal grandmother with probable AS.

Val's book also introduced the reader to the amazing Jim Sinclair who, despite multiple disabilities, brought people on the spectrum together in the Autistic Network International (ANI) and in the summer retreat known as AUTREAT.

Despite being divorced, raising her son alone, mourning her father's death, and dealing with the pressures of a doctoral dissertation, Valerie Paradiz emerged triumphant. She never became a tenured professor, but she accomplished so much more: Her legacy is the School for Autistic Strength, Purpose and Independence in Education (ASPIE). By creating this high school for high-functioning autistic and Asperger's adolescents, Val filled a gap, which had existed up to that point between primary school and college.

I will never forget the scenes in Val's book in which Elijah, an outgoing boy, reaches out, picks himself up after rejection, and reaches out again. Val is living proof that people with AS do not necessarily lack empathy. She is the very embodiment of empathy.

Val's book and her school made her highly respected in both the autism community and in the mainstream. Specifically, her accomplishments were described in *The New York Times*, *Redbook Magazine*, and *The Guardian*. Val's ASPIE model has been expanded and codified. In fact, Val told me that the self-advocacy curriculum would be published in the (AAPC) Teachers' Edition and in the Student Workbooks. Thus, Valerie Paradiz's work has had a truly positive impact on the public consciousness.

My next beacon did not afford me the encouragement in writing my book that Jesse and Val did; however, Michael John Carley's support group for Asperger's Syndrome adults was invaluable in my life. I first attended the group in 2006 when it was meeting at Grace Church in Manhattan. Although I stopped attending due to the pressures of

writing my Master's thesis, I returned afterwards and became an enthusiastic supporter of the group, as well as of Michael's efforts on behalf of our community.

# Michael John Carley

Michael made a name for himself when he established the Global and Regional Asperger Syndrome Partnership, of which he is the Executive Director.

When I first met Michael, he was facilitating the support group for adults with Asperger's Syndrome. By that time I had read up on the condition and found it almost impossible to believe that Michael was "one of us." First of all, he appeared happy and confident. Even after nearly five years of interacting with AS persons, I have never encountered anyone like Michael. He has a career, a wife, and children – a relative rarity in our world. Moreover, I never observed in Michael any of the obsessive characteristics, which typify AS people. Nor did he seem to have the Asperger's narrow and unusual preoccupations such as knowing train schedules by heart. When I asked Michael how he could be devoid of the typical AS symptoms, he replied, "I wanted to have what other people have." Thus, Michael John Carley succeeded in transforming himself. There is a saying, "if you can't make it, fake it." I believe that Michael initially "faked" neurotypical (i.e. non-autistic) behavior, but that his brain ultimately rewired itself to eliminate the glaring AS symptoms.

Michael's leadership of his support group was firm but compassionate. He calls himself "a happy person," and thus allows us to believe that happiness is not beyond our reach. What I find amazing in Michael is that he has the choice of "passing," yet chooses not to "pass." Instead, he has become a major leader and helper to those of us who do not have this choice.

In Michael John Carley's book, Asperger's from the Inside Out, Michael acknowledged that he had AS symptoms as a child. The book revealed that it was only when his son was diagnosed with AS that Michael came to the insight that he, too, was on the spectrum. His journey into his past, as well as his advice to his readers to "walk the walk," gave me the courage to do the same. In "walking the walk," we who live with AS can learn to forgive ourselves for our past inappropriateness, and also to forgive others who have rejected us due to our unacceptable behaviors.

In the book's discussion of disclosure, Michael supported those who wish to disclose their AS. At the same time, he encouraged respect for those who do not wish to disclose "for the common good." Such disclosure may mean, for example, the loss of a job. Michael also counseled us to be patient with family members who may initially be unable to accept our diagnosis. He added that some people will trivialize our diagnosis as "the latest fad."

One of the most powerful parts of Michael's book was the story of Michael Bembrick, whose mother is active with GRASP. (Another value of Michael's organization is that it offers help to family members and other loved ones of people with AS.) The handsome

and talented young Michael Bembrick came to the support group only once, but he did not return. He told Carley that some of the more challenged group members distressed him. He later committed suicide. The book analyzed incisively the real reason for the suicide. It was not "Major Depression," but rather the isolation experienced by so many of us on the spectrum.

This book is a virtual goldmine of information regarding the medical, psychological, and cultural issues surrounding AS. In person, as well as in his book, Michael confided that he considers himself an alcoholic. He has not had a drink for many years. I found it interesting that Michael and I have this addiction in common, although Michael is able to stay sober without being in a program. Michael added that people with AS often have a high tolerance for pain and that this factor enables him to resist the temptation of alcohol. Relatively few of the mental health articles and books I have read list alcoholism and drug addiction as co-morbid conditions in persons with AS.

Michael tellingly counters the belief held by many that we on the spectrum are incapable of empathy. He distinguished sympathy, or concern for the suffering of another person, from empathy, which he views as knowing what the other person is thinking. Michael added that once we on the spectrum are made aware of what the other person is thinking, we can be sympathetic. Michael's section on empathy brilliantly clarified that we on the spectrum are not incapable of concern for others. This is of utmost importance because it is the erroneous belief that people with AS lack empathy (or sympathy) that leads to the even more erroneous, and dangerous, belief that, due to this supposed deficiency, we have a predisposition to crime.

Another section in Michael's book that is of great value to people on the spectrum is the "Toolbox." Here Michael laid out strategies for people with AS, namely:

- -Be more thick skinned and less dependent on the approval of others.
- -Have a stronger tolerance for failure.
- -Distinguish needed criticism from unnecessary criticism.
- -Know our legal rights to accommodations at school and at work.
- -Do not feel that we are always right.

Michael's book also contains the advice to join support groups. Michael Carley is not just an advocate for people with AS. He is truly an advisor and a source of great support. Moreover, his greatest hope is to see GRASP able to function without him. For Michael, GRASP is not about his ego, but about the people to be helped.

I was pleased to discover that even before GRASP existed, and prior to the publication of Michael's book, his support group for adults with AS received positive publicity in an extremely informative article in *The New York Times*. GRASP received mainstream publicity on WFAN, the largest all-sports station in the United States. Moreover, there was positive publicity on NPR's "The Infinite Mind," and also on NEWSWEEK ON AIR. The Naperville, Illinois Asperger Teen Group received exposure in *The Chicago Tribune*. With regard to Michael's book, it received praise from the President of Autism Speaks, from actress Sigourney Weaver, and from noted author and professor Temple Grandin.

It is my hope that Michael John Carley and his book Asperger's from the Inside Out, as well as GRASP, will be a segment on a program such as Oprah Winfrey's. Then, millions more Americans will know Michael and the AS population. However, both Michael's book and his organization may be deemed to have already impacted the public consciousness.

GRASP has annual benefits, and at the 2010 Benefit John Elder Robison was awarded the "Distinguished Spectrumite Medal." I consider him a Beacon because he is one of the rare persons who works with both GRASP and Autism Speaks. He inspired me by his openness to addressing both the medical and the socio-political aspects of Asperger's Syndrome.

#### John Elder Robison

Robison's bestselling autobiography Look Me in the Eye begins with a Prologue, which concluded with the statement, "I am proud to be an Aspergian." According to Robison, Asperger's Syndrome is not a disease, but rather "a way of being." Another important feature of the Prologue was the preliminary portrait of himself, which included a misdiagnosis of schizophrenia due to inappropriate interaction with others. Robison was also diagnosed with "social deviancy." His explanation for his lack of eye contact was that not looking at the person speaking to him enabled him to take in what the speaker was saying. Many people consider lack of eye contact to be evidence of a guilty conscience. This is especially true in police interrogations. Robison also recalled his clumsiness in childhood, which is common among children with Asperger's Syndrome.

The section of Robison's book entitled "The Little Misfit" depicted with excruciating accuracy the aching loneliness that so many children in the AS population experience. This is due to our inappropriate behavior as well as to the lack of tolerance on the part of our peers and teachers. Robison was devastated by one little girl's rejection of him when he patted her on the head as he patted his dog. He wept when another child refused to hear him expound on dinosaurs and just walked away from him. What Robison powerfully makes clear is that AS children retreat into their own worlds, not out of a desire to be apart, but to spare themselves further hurt.

Robison's section on empathy was especially incisive because it exposed the insincerity of people who are not on the autism spectrum. When hearing of a terrible accident, young Robison would smile out of relief that it had not happened to him. Contrary to the belief of those who witnessed Robison's smile, he was not taking pleasure in the pain of the accident victims. Robison's brutal honesty exposes the falseness of the self-righteous people who want to appear kind.

In "The Dogs Begin to Fear Me," Robison described his mischievous practical jokes, which he played on his younger brother. Robison labeled the little fellow "Varmint." Robison's penchant for playing somewhat malicious practical jokes corresponds with

the description of the young boys treated by the psychiatrist Hans Asperger. In addition to the inappropriate behavior evinced by Asperger's charges, these boys manifested "malice." Neither the "malice" of Asperger's boys, nor the "mischievous" jokes played by Robison, portended future criminal behavior or violence. According to Robison, his hurt turned into anger, and then expressed itself in the jokes on his brother.

Robison's section "I Drop Out of School" applies to many of us on the autism spectrum who have technical gifts. Robison's test scores (the top 99%th percentile of the nation's IQ's) reflected his confidence in his abilities. He liked to play the role of teacher to younger children. Despite the prevalent view of people on the autism spectrum as computer geeks, a significant number of us have made careers as teachers, and even as professors. Among my Beacons there are authors who have been highly successful in the teaching field.

The section on his career path affords a valuable lesson for us on the autistic spectrum. Robison was unable to handle a promotion to an executive position because he was not "a team player." We who have AS, or autism, need to select careers that do not expose our flaws. Career counselors may be of great value in the professional choices we make.

Robison's section "Becoming Normal" should give all of us on the spectrum food for thought. As Robison increasingly became more appropriate and "normal" in his behavior, there was a decrease in his uncanny ability to perform complex technical tests, such as on musical instruments. It would seem that normality has a price: The loss of savant-like gifts. In fact, Michael Carley once told me that the most remarkable savants are usually the most dysfunctional. Fortunately, Robison became highly proficient and well-respected in his later career of rehabilitating high-end cars. By that time he was also able to interact appropriately with others.

Among those attending the GRASP support group meetings, there are few who have long-lasting (if any) romantic relationships. Robison's first marriage failed, but in his second marriage, in part through his love for his son, he transformed himself. In this respect he is like Michael Carley.

I was most pleased to see how positively Robison's book has impacted on the general public. *Kirkus* gave his book a very good review, as did *Amazon.com* in its "Inquiring Minds" piece. *Publisher's Weekly* included Robison among "The Best of 2007." Most notably, Erin Moriarty of CBS's *Sunday Morning* did a very complimentary segment on John Elder Robison.

The recipient of the 2009 "Distinguished Spectrumite Medal" was Stephen Shore. I spoke briefly with him and had the chance to commend him on his fine book, *Beyond the Wall*, as well as on his remarkable efforts on behalf of our community.

# **Stephen Shore**

This amazing man is one of the healers our community so desperately needs. His pursuit of a doctorate in special education and his advocacy on our behalf make him one of our great pioneers. Like John Elder Robison, Shore sees autistic spectrum conditions as "a way of being," or as "another order," rather than "a disordered deviant way of existing."

Shore's book lists his "Special Interests," which encompass the mechanical as well as the intellectual. Cats, of course, appeared on that list.

In adulthood, Shore's career goals changed radically - from the mechanical area to music, and to the field of special education. John Elder Robison, Valerie Paradiz, and Michael John Carley might be viewed as Renaissance people.

Typical for us on the spectrum, Shore was incorrectly diagnosed as having "atypical development, psychotic behaviors, with strong autistic tendencies." It is noteworthy that Shore grew up with a brother who was mildly mentally retarded and epileptic. It is quite possible that this brother figured in Shore's later career choice of special education.

Shore's mother was very supportive of him. His father was barely aware that young Stephen had any disability. The word "autism" was just like any other word in the Shore family. Shore's mother played with him even when he was totally unresponsive.

For young Stephen Shore school was traumatic. He, as well as many children on the spectrum, had coordination issues, which precluded successful participation in sports. Shore's teacher claimed that he was incapable of learning mathematics. Yet, the adult Shore taught math at the college level and had an accounting career, cut short only due to his lack of social skills. For Shore, college proved a relief after years of social ostracism.

In another section of his book Shore discussed his sensory issues. He spoke of his uncanny ability to hear whispers from another room. Shore was unable to ride in a crowded subway due to the noise and the smell. To avoid this torture he rode his bicycle to work. As my autobiography revealed, I myself have major sensory issues. Moreover, my reading on autism taught me that many of us on the spectrum have these issues regarding smell, noise, texture, and taste.

The very sensitive subject of the alleged lack of empathy among autistic persons is handled most intelligently in Shore's book. He explained that he had originally lacked the "theory of mind" required in situations such as giving up one's seat to an elderly person. Once Shore realized what was expected, he was embarrassed by his failure. He simply had not thought of standing up. To my way of thinking, true lack of empathy would exist in the following situation: A person does not give up a seat, in full knowledge that an obviously frail senior citizen or a disabled person is standing. Moreover, this person would know that standing up is expected behavior.

What I most admire in Shore is his resiliency and flexibility when his goals in both finance and music were frustrated. He just picked himself up and aimed for the next objective. Undreamed-of success came to Shore in his special education career, especially in teaching autistic children through music. Sadly, quite a few persons on the spectrum despair after seeing their dreams shattered and do not pick themselves up. That is why support groups are so vital for those who have been diagnosed with autism or Asperger's Syndrome.

A major insight of Shore's is that the autism community needs to advocate for itself, united with one voice. I wholeheartedly agree with Shore.

Shore's book also contains a section entitled "Getting Ready for College," which is a strategy-map designed to aid the autistic/Asperger students in finding their way on this new terrain.

Fortunately, Shore's impact on the public consciousness has been significant. He has appeared on Public Radio and on Newsweek National Radio. Shore's book has been discussed in the Chronicles of Higher Education, the Boston Globe, and in USA Today. Leaders such as Stephen Shore are invaluable when their lives and works shatter negative stereotypes of people on the spectrum.

The next Beacon is a woman who achieved not only a professorship, but also married and raised children. Sadly, I never had the pleasure of meeting Liane Holliday Willey.

# Liane Holliday Willey

My acquaintance with this Beacon was through her book *Pretending to be Normal*. Holliday Willey's story must amaze many readers who think they know people with AS- all lonely computer geeks. This woman not only has a successful college teaching career, but is also married with children. Holliday Willey expressed in her biography her total lack of fear of speaking before large groups. In fact, she also had a theater background. Just as Stephen Shore could relate to his students, so did Holliday Willey. Just as Carley and Paradiz have succeeded in raising children, so has Holliday Willey.

Unlike Shore, Holliday Willey recalled her years in primary and secondary school as happy. Her years at a large university, however, proved a great challenge. It was at college that Holliday Willey experienced rejection and ostracism. Moreover, the large campus baffled her, and she constantly got lost and came to classes late, or not at all. As a result, her grades plummeted. The author added that even in adulthood she gets lost, and she related a horrible experiences of being unable to find her car while on a trip in San Francisco.

Like so many of us with AS, Holliday Willey described sensory issues. When she found herself in a place that provoked these issues, she would lose her footing and become dizzy, shaken, and nauseous. Despite her love for her babies, Holliday Willey would become so violently revolted at the sight and smell of "nasty" diapers that she had to leave the room and lie down.

Holliday Willey's support system in adulthood consisted of two very close female friends who gave her honest feedback when she behaved inappropriately. As her daugh-

ters grew older, they unstintingly enlightened her when her conduct was unacceptable. For example, they corrected her when she yelled out, "what a horrible smell!" They also reminded her that not everyone wanted to hear her talk endlessly about her favorite subjects.

Like many of us on the spectrum, Holliday Willey became less inappropriate with maturity. The author wondered if her gift as an author had diminished as her AS inappropriateness lessened. In this respect, she is similar to John Elder Robison. It is not certain that in most people on the spectrum the diminishing of inappropriate behavior is always accompanied by a diminishing of giftedness. As the autobiographicalsegment this book reveals, my improved social skills were accompanied by improved, as well as new, abilities.

There is one scene in Holliday Willey's book that brought back the terrible experience of acquaintance rape I described in my autobiography. Holliday Willey was sitting in an empty auditorium, waiting for her class to arrive, when a young man entered the area and began to talk to her. She did not pick up on his signals until he was about to rape her. Fortunately, a male student entered the room at that point, and the strange man left hurriedly. The author, like many females on the spectrum, was socially and sexually naïve.

Liane Holliday Willey is highly respected in the autism community, especially since she coined the term "Aspie," which many of us use. With regard to her impact on the public consciousness, it was very positive. Pretending to be Normal became an international bestseller. Moreover, Holliday Willey has been the subject of articles in major newspapers, such as The New York Times and The Washington Post. In addition, she was a featured guest on The Infinite Mind, BBC Radio-4. Finally, Holliday Willey has been the subject of two documentaries, Asperger Syndrome, and Crossing the Bridge with Tony Attwood.

In 2003, when I was studying at John Jay College, I came across a page in my textbook on abnormal psychology that changed my life. There was a picture of Temple Grandin and an essay describing her life with autism. Although my book deals with works by authors diagnosed with Asperger's Syndrome, I am including Dr. Grandin because she is considered the "grandmother" of the autism movement, which now also includes those of us diagnosed with Asperger's Syndrome.

# Temple Grandin, Ph.D.

In my psychology textbook Dr. Grandin was described as a child who had tantrums, smeared her feces, and did not speak until the age of four. Yet, she became a designer of cattle facilities and an internationally known author and lecturer on autism. Moreover, Dr. Grandin is a professor of Animal Sciences at Colorado State University. Reading further about this remarkable woman, I recognized her qualities in myself, such as the inability to read social signals and the aversion to being touched. The section in

the textbook on Dr. Grandin also contained information about Asperger's Syndrome. There I saw myself uncannily mirrored.

I wrote Dr. Grandin a long letter expressing my admiration for her triumph. She actually called me! Her calm voice and relaxed manner belied the descriptions of her as being loud and obviously different. Dr. Grandin told me that she believed I have Aspergers' Syndrome and directed me to her website, where I learned a great deal about the sensory issues of people with autism and Asperger's Syndrome.

When I read Dr. Grandin's book, *Emergence. Labeled Autistic*, I was even more inspired. She was diagnosed with autism before the diagnosis of Asperger's Syndrome existed. Although nonverbal in early childhood, the author more than made up for it by asking her mother repeated questions and having fixations on various topics such as elections. The DSM-IV excludes children with speech delay from an Asperger's diagnosis, but Temple Grandin proved that the boundaries between the diagnoses of autism and Asperger's may, in reality, be blurred. Dr. Grandin's high intelligence also challenges the stereotype that autistics usually have mental retardation.

One of the most moving aspects of the book was the unconditional love Temple Grandin's mother expressed in exquisitely articulate letters to her child. She also constantly defended her daughter against school authorities. The schoolgirl Temple loved to play practical jokes on people. This reminded me of John Elder Robison, of the boys at Hans Asperger's school, and of myself.

According to Temple Grandin, the difference between autism and Asperger's is that autistics think in pictures, whereas people with Asperger's think verbally. It certainly applies to the author, but many Asperger's computer "geeks" must think in pictures when they design programs.

The most striking aspect of Dr. Grandin's life is that it reflects the dynamic nature of autism, and of other disabilities as well. Temple Grandin was fortunate in having friends who gave her honest feedback regarding her behavior. She had the humility and ability to be self-critical, which allowed her to evolve. Even in adulthood, Temple Grandin can accept constructive criticism and observe her own conduct. Thus, she continues to evolve. Many people without disabilities lack the humility to accept criticism. I believe that Dr. Grandin's insight into herself, and into others, is at the root of her professional and personal development and success.

Temple Grandin's book, and indeed her whole life, represent far more than just intellectual achievements. *Emergence* is filled with caring for others. The author shares unstintingly the techniques that allow her to live with her behavioral and sensory issues. For example, the Squeeze Machine is a product of Dr. Grandin's insightfulness into both cattle and autistic persons, who need the type of soothing hugging the machine can effect.

Ultimately, Temple Grandin's achievements transcend any label. At a time when no one could conceive of an autistic person even finishing primary school, Temple Grandin was awarded a doctorate. Her life and her book teach us all that, with determination and integrity, we on the spectrum can achieve our goals.

Dr. Grandin's writings and lectures have powerfully impacted the public consciousness. The author and her books have been discussed in the mainstream media, both nationally and internationally. Moreover, HBO produced a film on her life, which will be discussed at a later point in this book. Information on Asperger's Syndrome is not central in Dr. Grandin's diagnosis or in her writings. However, in the near future Asperger's will likely be simply subsumed under the rubric "autism spectrum."

Now I turn to a discussion of five authors diagnosed with Asperger's Syndrome. Although I greatly admire these authors, their books had little or no impact on the consciousness of the general public–specifically with reference to Asperger's Syndrome.

In the cases of Dawn Prince-Hughes and Daniel Tammet, their books did enjoy mainstream attention, but the coverage of these books related to Prince-Hughes's bonding with gorillas and to Tammet's almost unique level of savantism. Whereas the autism of these authors was emphasized, their Asperger's Syndrome received only peripheral attention.

In the cases of Zosia Zaks and Wendy Lawson, their books were reviewed in blogs, rather than in the mainstream media. The attention the books received was predominantly with respect to the authors' autism and/or their lesbian relationships rather than to their Asperger's Syndrome.

Finally, in the case of William Stillman, the coverage his book enjoyed was not in mainstream media, but rather in blogs and journals related to spirituality and parapsychology. The focus in this coverage was on autism, rather than on Asperger's Syndrome.

# Dawn Prince-Hughes

This author, who wrote *Songs of the Gorilla Nation: My Journey through Autism*, expressly stated that she had been diagnosed with Asperger's Syndrome. However, the title of her book reveals at once that she identifies herself as having autism rather than Asperger's Syndrome.

The Introduction to Prince-Hughes's book tells the reader that it is a book about autism, and that there are two types of autism: The classic type and Asperger's Syndrome. The author explains some of her symptoms: During times of stress she must wear dark glasses and earplugs; she is enraged when touched; and she has a hard time dealing with groups of people.

Part One is entitled "A Life without Song." Prince-Hughes related that she emerged from the darkness of one type of autism to autism in another context. She learned from the gorillas she studied how to live with wonder, and to discover the feelings that poetically inform each human life.

Prince-Hughes described her early childhood. She began to speak before she was a year old and could walk at the age of ten months. She needed order and routine to protect her against the chaos of autism. Prince-Hughes also had sensory issues, such

as being addicted to the warmth of the oven and the fragrance of bacon being fried in her grandparents' home. The author also explained that spoken English was the second language for her, and written English was her first language.

Prince-Hughes discussed the autistic-like qualities of her relatives. These included wearing the same clothes daily or carrying pi to 200 places. When a young boy in her family was diagnosed with Asperger's Syndrome, Prince-Hughes was enraged to see herself mirrored in his symptoms. She also resented the fact that her young male relative's diagnosis provided legal rights to him, whereas she had had none. (Later in the narration, she revealed that she herself received a diagnosis, which aided her obtaining her legal rights, such as finding housing.)

Countless readers on the spectrum will identify with the author's traumatic school years. Dawn Prince-Hughes was ostracized and physically assaulted. She recalled her head being dunked in the school toilet. During those years she found gay male friends who accepted her as she was, which somewhat eased her misery. However, her school-mates in high school discovered that she preferred to be with girls and called her "queer." Prince-Hughes almost never fought back when she was tormented because the gorillas never retaliated against their tormentors.

The author left high school and used alcohol and drugs to ease her pain. Because she could not pay the rent on the room in which she lived, she became homeless. In order to be able to find a place to live, she found work dancing in a strip club. Prince-Hughes sought peace in the local Woodland Park Zoo, where her friendship with the gorillas began.

Part Two of Dawn Prince-Hughes's book is entitled "Songs of the Gorilla Nation." The author wrote a report on her observations of the gorillas and showed it to the zoo's director of research, who felt that the girl was capable of doing graduate work independently. He agreed to sponsor research projects for Prince-Hughes to work on with other people. The author saw that the gorillas were treated the way people treat autistics and the mentally ill. People yelled into the cages, calling the gentle apes lazy and dangerous. However, Prince-Hughes saw in the gorillas the capacity for spirituality. She wrote poetry about these animals and knew all their names.

When Prince-Hughes was awarded her Master's degree in anthropology, she celebrated by going on a cruise by herself. On the boat she met Tara, who became her lesbian-partner and co-parent of a son. The author's partner also explained human behavior to her. Tara found living with Prince-Hughes difficult, due to her temper and screaming attacks. This is what prompted Prince-Hughes to seek a diagnosis. Indeed, it was Asperger's Syndrome, and she was prescribed three medications for her anxiety and trouble sleeping.

In Part Three, "How Can I Keep from Singing," Prince-Hughes finally tasted success. She was awarded her Ph.D. after her Defense Committee members admitted that they could not compete with her immense knowledge of gorillas. Moreover, the author wrote two books and found publishers for them. Prince-Hughes also became an adjunct professor. During this time, the author and Tara, by means of *in vitro* fertilization, be-

came parents of a son. Dawn Prince-Hughes was amazed to find that she was capable of being a loving mother. The author was soon inspired to become involved in the ape-advocacy movement, which opposed experimenting on apes. These advocates recalled how the Nazis used the Jews in experiments. Moreover, Prince-Hughes became interested in interspecies communication. The author observed that apes meet all the criteria of personhood: Empathy, abstract thinking, and the capacity to follow complex rules.

In the Epilogue, Dawn Prince-Hughes expressed the belief that she is the bridge between apes and humans, and also between autistics and "normal" people. Autism, according to the author, is a way of sensing the entire world, and of creating and knowing. Prince-Hughes hopes that all of us will become students of the gentle gorillas. In that way, a culture of one will mean a culture of all.

Since this author's story is amazing and inspirational, I was certain that her book would be reviewed by major newspapers. To my amazement, I found well over 18,000 discussions of Prince-Hughes's book, but only one was in a mainstream US newspaper.

The New York Times had a favorable review of the book and included a description of the author as having Asperger's. Such a person was depicted as often highly intelligent and as having interests in only one subject, to the exclusion of everything else. The Times piece described the loving and patient acceptance the gorillas showed the homeless Prince-Hughes. Moreover, the reviewer praised these gorillas as the salvation of the young woman because they taught her how to relate to people.

On the international level, I found a review of *Songs of the Gorilla Nation* in the *United Kingdom Times: Higher Education*. Very little about autism (let alone about Asperger's Syndrome) was included in this piece, which primarily addressed the behavior of gorillas as depicted in Prince-Hughes's book. The author was briefly described as an American woman with Asperger's Syndrome, whose experience taking care of gorillas in a zoo brought her peace. The critic added that it might have really been the apes, who took care of Prince-Hughes. However, that same critic acknowledged that it was amazing that an autistic person, of impaired ability to communicate, was able to understand gorilla bonding.

Both the New York Times review and the UK piece on Songs of the Gorilla Nation would have impacted the consciousness of only an intellectually high-level readership. From The New York Times piece, a reader's consciousness would have been somewhat impacted with regard to Asperger's Syndrome. The UK review would have had an impact with regard to primates, but an impact regarding Asperger's Syndrome would have been almost non-existent.

Kirkus Reviews, although not read by the average American reader, acknowledged Prince-Hughes as having opened a window into the world of autism and providing an unforgettable view. Since it is the world of autism into which that window is opened, the impact on any reader's consciousness would not be in regard to Asperger's Syndrome.

The overwhelming majority of the discussions of Songs of the Gorilla Nation emanated from blogs regarding autism, and also with respect to gay/lesbian issues. In

essence, there could be only the slightest impact on the consciousness of the general public with reference to Asperger's Syndrome.

#### Daniel Tammet

Tammet, who authored both *Born on a Blue Day* and *Embracing the Wide Sky*, is known as a prodigious autistic savant rather than as a man with Asperger's Syndrome. This is despite the fact that he writes informatively of his Asperger's diagnosis.

First, I will discuss Tammet's Born on a Blue Day, which made the author an instant world celebrity.

In the first chapter of the book, Tammet explained that he is on the autistic spectrum. He explained further that he has Asperger's Syndrome, a relatively mild and high-functioning form of autism that allows the person to lead a relatively normal life.

The author described his childhood and his family members. As a toddler, Tammet would rock back and forth and hit his head against the wall. He also had severe tantrums. Later he became a loner, who could speak to others but was basically quiet and aloof. For Daniel Tammet, the unconditional love of his parents enabled him to survive the difficulties of childhood. They made him believe in his abilities to achieve and supported him in all matters. His father was a mentally ill ex-soldier, who was nevertheless able to nurture his son. The author revealed that his younger brother exhibited the same childhood features, and also suffered from the same loneliness, anxiety, and fear of the future that he himself experienced.

Of great significance in Tammet's life was his temporal lobe epileptic seizures, which began in his childhood. Medications stopped the seizures. As Tammet matured, he was taken off the medications and remained seizure free. In a detailed chapter on temporal lobe epilepsy, Tammet described the symptoms and informed the reader that one third of all autistic children in Britain also develop temporal lobe epilepsy (TLE). The author cited Eve La Plante's book Seized, in which Vincent Van Gogh is mentioned as having had TLE. Referring to the La Plante book, Tammet noted that savantism could arise after an illness or injury to the brain. The author stated that he believed that his epilepsy left him with a fascination for languages. Tammet also expressed the belief that the stigma of epilepsy, and autism as well, was slowly disappearing.

As is the case with many children and teens with Asperger's, school was a painful experience for Tammet. He stressed that he wanted friends, but that his failure to maintain eye contact and his incessant talking about his pet subjects would cause people to avoid him. Thus, he was always lonely.

Completion of his school years at age eighteen was the first turning point in Tammet's life. He became a member of a volunteer youth organization and was sent to Lithuania. There he taught English and, for the first time, he had friends who did not find him strange. Tammet loved to teach, nurturing his students' abilities. He even

learned Lithuanian within a matter of weeks. Moreover, he managed to find his way around in the unknown surroundings, a challenge for most people on the spectrum.

Tammet's return home brought unemployment. He obtained a computer and went on line. It was on the Internet that Tammet made the acquaintance of Neil, who became his partner. When Daniel revealed that he is gay, his family accepted him and Neil. Tammet moved to Kent and lived with Neil. The two men created a website for language learning, which resulted in financial security for them.

The next turning point in Tammet's life was his winning a numbers contest, where he set a new British record for pi. He gave the prize money to the local epilepsy organization.

After that contest, Tammet became a public figure. He was a participant in a documentary film entitled *Brainman*. During the filming Tammet made the acquaintance of Kim Peake, who was the model for the film *Rain Man*. This was the first time Tammet met another savant. Scientists questioned Peake about his savantism. Peake was dependent upon his parents in all his activities. Despite his limitations, this man was kind and compassionate, reading to an elderly neighbor every evening. Getting to know Peake made Tammet grateful for his ability to function independently.

Back home in Kent, a newly-confident Daniel Tammet joined a Christian church. Like many of us on the autistic spectrum, Tammet enjoys the ritual aspect of organized religion. Tammet believes that we should all be treated with respect and kindness—because we are all unique and created in the image of God.

Daniel Tammet's next book, *Embracing the Wide Sky*, also inspired me; however, I already knew how amazing this man is. I will summarize the parts of the book that I found most enlightening.

First of all, Tammet displayed in the book great humility. Despite being one of only fifty persons in the world to be a prodigious savant, he stated at the beginning of his book that every brain is remarkable and unique, and that anyone can master a subject with passion and dedication. Although Tammet acknowledged that work alone does not produce genius, he added that genius is a result of innate talent, human qualities, love, and imagination.

The author rebutted the prevalent misconception that the brain cannot change after birth. He explained that the brain can change and grow due to neuroplasticity. Furthermore, Tammet noted that the cognitive decline associated with aging can be counteracted by actions such as learning a new language.

Tammet also challenged the belief that autistic savants cannot be creative. He explained that a person with High Functioning Autism (HFA), or Asperger's, can feel complex human emotions and contribute to society. The author stated that savant abilities are derived from the imaginative mind, and not from dry mechanical processes.

Tammet briefly described the evolution of an autistic person from a child, who rocked back and forth, to a brilliant but socially awkward scientist. The author referred to his book *Born on a Blue Day* to show that his Asperger's Syndrome did not prevent him from having a career, a relationship, friends, and enjoyable intellectual pursuits.

Two sections of Tammet's book were most fascinating to me: The Biology of Creativity and the Future of the Mind.

The Biology of Creativity

In this section Tammet stated that many believe that genius and madness go hand in hand, and that history has recorded great creative persons who struggled with mental illness or seizures. Van Gogh's seizures were described by the artist himself as "the storm within." The author noted that there were great writers who had epilepsy, and that John Forbes Nash, Jr. lost three decades to paranoid schizophrenia. Yet, Nash won the 1994 Nobel Peace Prize.

According to Tammet, researchers have found a biological link between mental disorders and original creative thought. Ostensibly, low levels of brain inhibitors and high intelligence make it possible to shut out stimuli extraneous to the brain's needs. Tammet's father had schizophrenia and was swamped by mental associations and a chaotic flow of thinking. However, Tammet is able to control the "storms."

Tammet referred to Professor Michael Fitzgerald, who believes that the intense focus, persistence, power of observation, great curiosity, and compulsion to make sense of the world are all Asperger's Syndrome talents. Fitzgerald added that these qualities have resulted in changing the world.

The Future of the Mind

Tammet expressed concern with the scientists who use as "brain lifts "medications meant for people with serious illnesses. For example, Ritalin, which is meant for children with ADHD, is being used by students as "brain boosters" before taking tests.

The subject of creating a part human/part computer is also disturbing to Tammet. He noted that cochlear implants are not pure simulations of the natural auditory system. Tammet revealed that he is appalled by the idea of "upgrading" his humanity. He also expressed doubts as to whether a machine can replace richness and subtlety of human intelligence.

Envisioning a humane future, Tammet cited the success of virtual reality in teaching autistic children. He expressed hope for the success of a vaccine, which would clear from the brains of people with Alzheimer's the plaque formations, which are believed to be the key cause of the disease. Finally, Daniel Tammet stated that we can all use our brains to imagine a brighter tomorrow.

Not surprisingly, I found many articles on Tammet and his books, but with little (or no) focus on his Asperger's Syndrome.

One newspaper did address Tammet's Asperger's Syndrome. *The Sunday Times* (London) described Tammet as being blessed with remarkable mental gifts, but for whom Asperger's Syndrome is a struggle.

The New York Times featured an article discussing Tammet's Born on a Blue Day: Inside the Extraordinary Mind of an Autistic Savant, which was on The New York Times best-seller list for two weeks. In the article, Asperger's Syndrome received only a brief mention as a form of high-functioning autism with which Tammet was diagnosed at age 25. Otherwise, Tammet was described by himself and by the reviewing journalist

as autistic. The author of the article noted that Tammet sees himself as an advocate for people with autism. The very detailed coverage of Tammet and his book must certainly have had a strong impact on the consciousness of those who read it, but with respect to autism and not Asperger's.

In another issue of *The New York Times*, the Health section included a piece in which Tammet's *Embracing the Wide Sky* was discussed as one of the books by a person with Asperger's Syndrome. The focus, however, was not on Tammet's AS. Rather, the reviewer dealt in detail with Tammet's math and linguistic savantism, which enabled him to speak Islandic in a television interview. This interview occurred just one week after studying the language. Tammet's Asperger's Syndrome is minimized in this piece, while his remarkable mind received the most journalistic attention. Even if the article had focused on Asperger's Syndrome and had an impact on the consciousness of readers of *The New York Times*, this would not translate into an impact on the consciousness of the general public.

On an international level Tammet has also received significant publicity. One example is *The Guardian*, published in the United Kingdom. In the review, *Born on a Blue Day* is said to allow the reader to find out how it feels to be a savant, whereas in *Embracing the Wide Sky* the reader learns how a savant thinks. Although Tammet's epilepsy is briefly mentioned in this review, there is nothing on Asperger's Syndrome. The writer of the piece notes that most savants cannot explain how they do what they do, whereas Tammet can describe what he sees in his head. This critique would appeal only to a limited high-level readership. Moreover, given the absence of even the mention of Asperger's Syndrome, there could be no impact on the consciousness of any member of the reading public in regard to AS.

The next two "Beacons" offer valuable information on Asperger's Syndrome. However, their books have not enjoyed wide exposure in the mainstream media and, therefore, could not impact the public consciousness.

First, I turn to Zosia Zaks, who has written a book with a "How To Live with Asperger's/Autism" guide.

# Zosia Zaks

I met Zosia Zaks at the 2008 Disabilities Studies Conference held at Baruch College in Manhattan. She spoke about autism. After the session we had a brief conversation. Zaks informed me that she was diagnosed with Asperger's Syndrome, but that her book was dedicated to adults with autism. I told her I would buy her book.

Zaks's book, *Life and Love: Positive Strategies for Autistic Adults*, is a virtual roadmap for all autistic adults, who face major challenges in everyday life. Her Sensory Emergency Kit, which includes sunglasses and earphones, is an invaluable tool for all persons with such hypersensitivities.

The author's tips on navigating housing and relationships are brilliant because she provided a checklist for different routines. For example, in the morning she listed taking a shower and using a deodorant.

Zaks's counseling of autistic adults is probably as good, if not better, than that which is provided by mental health professionals who are not on the spectrum. It is for this reason that we who have Asperger's Syndrome should be encouraged to go into the field of mental health counseling.

The author also writes openly of her long-term lesbian relationship and of dealing with her Asperger's issues in this context. She belies the stereotype that we on the spectrum have no lasting romantic relationships.

When I searched for publicity relating to Zaks's book, I discovered that she is well-known to the autism and lesbian communities, but not to the general public. Zosia Zaks, who is very reserved, does not seem to be concerned with becoming a public figure.

The next author, whom I never had the pleasure of meeting, is also in a committed lesbian relationship: Marriage.

# Wendy Lawson

This woman, who wrote *Life Behind Glass*, has accomplished far more than many of us who are not disabled by an autistic spectrum disorder. After being incorrectly diagnosed with schizophrenia following several suicide attempts, Lawson became a nurse, a social worker, and ultimately an adult educator. Although diagnosed in 1994 with Asperger's Syndrome, Lawson has continued to identify herself asautistic. Her published works refute the misconception that autistics lack language skills. Like Holliday Willey, Lawson felt like a perpetual onlooker who needed to blend in so no one would notice how apart she really was.

The obsessive thoughts and behaviors associated with AS aptly described Lawson, who wrote copious letters to the objects of her adoration, and then experienced painful rejections.

Wendy Lawson described herself as being fascinated by rich colors and by the spinning wheels of a bicycle turned upside down. I believe that all of us on the spectrum, even those without speech, perceive as wondrous things of which most people are unaware. Perhaps we are AWEtistic.

Lawson wrote that she finds the written word easier to comprehend than the spoken word. When she was employed as a nurse, she was not able to tolerate being advised of new procedures she had to learn. Moreover, like so many of us on the spectrum, Lawson had difficulty with unexpected job directions and felt panic at the surprise factor. These issues confront people with learning disabilities. In many cases, the United States Americans With Disabilities Act requires reasonable accommodations, such as written instructions and job coaches.

Wendy Lawson related how much she enjoys talking about people and things she loves *ad nauseam*. She described her passionate quest for information on autism and depression. We on the spectrum do tend to bore people when we speak incessantly about our preoccupations.

Lawson found it difficult to make and keep friends because people found her egocentric. She had to learn to show concern for others. Although many of us on the spectrum are often self-obsessed, we can learn to talk less about ourselves and to listen more to others. Family members and friends may provide constructive criticism, which helps us overcome egocentric behavior.

Lawson was also considered eccentric, which sometimes caused the girls whose friendship she sought to reject her. Eccentricity may, in some instances, be considered charming or cute, if it elicits amusement rather than boredom or annoyance.

Wendy Lawson's life is a major triumph. I wish that her book had impacted the consciousness of the general public. I found no material on her in mainstream publications, but Lawson is well-regarded in the autism and lesbian community blogs. On her website she shares news about her life with those who are interested.

I now turn to a male author with Asperger's Syndrome who has impacted the public consciousness, but specifically in the areas of parapsychology and spirituality, rather than with regard to Asperger's Syndrome.

#### William Stillman

Author and activist Stillman was a guest speaker at our GRASP Support Group in 2008. He spoke of the uncanny link many autistics have with God. When one of the group members angrily accused Stillman of being born again and against gays, Stillman gently told him that he, too, is gay.

I was deeply touched by Stillman's gentle radiance and purchased his book soon after the meeting. Although Stillman initially describes his issues in childhood with Asperger's Syndrome, the rest of his book is concerned with children and adults he labels autistic. Stillman's primary focus is on their spirituality. Autistic children pray and often bless others. Stillman deemed it miraculous when a mother begged forgiveness of her autistic son for her false belief that he had no intellect. The boy, who had never spoken before, told his mother that she was sweet.

In a section entitled Divine Experiences, Stillman explored the amazing connection between autistic people and animals, including a faun, a horse, and ladybugs.

Stillman has made a name for himself in the realm of parapsychology and spirituality in general. His book was reviewed in the *Journal of Parapsychology*. Stillman, however, has not impacted on the consciousness of the general public with regard to Asperger's Syndrome. I hope that in his future lecturing he emphasizes his own Asperger's Syndrome and clarifies that Asperger's is on the autism spectrum.

After reading the works authored by my Beacons, I hope that educators and mental health professionals will expand any narrow views they have held regarding their students and clients who have AS. People whose attitude is neutral towards persons with AS may be enlightened by reading about the men and women to whom I have paid tribute.

Sadly, those who are prejudiced against our population will probably view these Beacons as exceptions to the rule that people on the autistic spectrum are typically low-functioning, and sometimes even dangerous.

The next section of this book will deal with writings by psychiatrists and psychologists on the subject of Asperger's Syndrome.

# 1. Mental Health Professionals on Asperger's

Since these writings are unlikely to reach the general public, their impact on the public consciousness will be limited. However, the varied findings of the professionals will enlighten parents, teachers, friends, and the Asperger's Syndrome population.

# Findings of Psychiatrists and Psychologists

My approach to this section will be to discuss the findings of these mental health professionals with regard to Asperger's Syndrome. I will address these findings in chronological order, beginning with Hans Asperger's 1944 thesis and concluding with Valerie L. Gaus's on the use of cognitive-behavioral therapy on adults with Asperger's Syndrome

# Hans Asperger, Die 'Autistischen Psychopathen' im Kindesalter (1944)

Uta Frith, in her 1991 text entitled Autism and Asperger Syndrome, translated into English Asperger's thesis published in 1944. Frith also added enlightening annotations to the text. The English title is 'Autistic psychopathy' in childhood.

Asperger wrote his paper based on his work with young boys who had severe conduct problems and were often expelled from school. The boys were boarded in his "ward." According to Asperger, the children had a personality disorder. However, they were not psychotic and suffered no personality disintegration, as is the case in schizophrenia. Moreover, Asperger contended that the milder form of autism found in the boys he studied was not at all rare. Case histories of four such boys were provided by Asperger as examples of the disorder. I will briefly summarize what is described in the text.

Fritz W. was expelled from school for assaulting other pupils. His father was eccentric and one of his grandfathers was exactly like Fritz. Fritz had excellent abilities in mathematics. With the innovative remedial education Fritz enjoyed under Dr. Asperger's aegis, he evinced steady development and had "numerous genuine relations".

Harro L., although less severely disturbed than Fritz, was expelled from school for going into furies. He also engaged in sexual play with other boys at school. Harro's father was just like Harro. The boy was clumsy and had difficulties with the mechanical aspects of learning. Harro showed independence of thought and experience. It was possible to talk with him as an adult and to learn from him. The other boys on the ward ridiculed his appearance and the dignity with which he carried himself.

Ernst K. failed at school and abused other children, both verbally and physically. He was a troublemaker. Although he spoke like an adult, he had difficulties with

the routine demands of everyday existence. His father was an eccentric loner. Testing revealed what is known as dyslexia today. Ernst told people untrue stories, which he may have believed himself.

Hellmuth L. suffered asphyxia at birth and had convulsions. He talked like an adult even as a toddler. He was grotesquely fat and had breasts and hips like a female and a tiny skull. Nevertheless, he possessed an immobile dignity. In childhood he was malicious, destroying objects. He engaged in rituals and was pedantic. Frith noted that Asperger believed that severe autism was due to a brain insult rather than to constitutional causes.

I included the descriptions of the four boys because any readers on the autistic spectrum will probably recognize aspects of the boys' background and personalities in themselves.

Asperger explained the special type of education needed for his special pupils. First, there should be no affect shown in educating these children. Asperger explained that the teacher should never be angry, but always calm, and not aim to become loved by the pupils. In addition, Asperger cautioned against a teacher becoming involved in arguments with the children. He specified that instructions should be given over the child's refusal in an objective, general way and in a soft and sing-song voice. Finally, Asperger emphasized that the teacher must feel genuine care and kindness towards the children because these children see through insincerity.

Asperger also detailed both the positive and negative aspects of the disorder, but he acknowledged that the positive aspects do not outweigh the negative ones. Asperger described three types of persons with the disorder, ranging from the "highly original genius," to the "weird eccentric who achieves little," to the "automaton-like retarded individual." According to Asperger, his children had aristocratic faces with a worried expression as well as "a glance that does not meet glance as it does when unity of conversational contact is established." Hans Asperger also attributed to his subjects an ability to judge character, but Frith noted that people with Asperger's Syndrome are "behaviorists," who judge by actions rather than words. Asperger stated that children with this disorder usually have no siblings. Sexually strong actions such as masturbation and homosexuality are common. Interestingly, Asperger also found that hyposexuality and lack of desire to have children are common in autistic personalities. Asperger labeled them as "instinctually disturbed" and noted that most of them remain solitary, unmarried, and childless. Asperger described his subjects as "egocentric in the extreme" and lacking any respect for others, treating everybody as their equal. The subjects were also described as being unkempt and unwashed even as adults in an academic setting. Asperger found that his subjects "had no sense for personal distance," would lean on strangers, and would start conversations with strangers on topics of the subjects' own choosing. Frith noted here that this is due to inability to distinguish their mental state from others, Although poverty of emotion is often attributed to persons with this disorder, Asperger added that the boys in his ward displayed severe homesickness, often crying for days. Frith also observed, regarding Asperger's instructions on education,

that Asperger believed (contrary to the widely-held belief that autistic children are incapable of intense emotion), that the children could relate to a teacher in an emotional manner.

Asperger's section on "[t]he Social Value of the Autistic Psychopath" is a defense of his charges. Frith noted that Asperger sought to protect his charges in his Austrian facility from the euthanasia that was the fate of defective children at the hands of the Nazis. In fact, Frith added that Asperger's original paper described a severely autistic boy, who became an astronomy professor, as "by no means exceptional." However, in his 1952 paper he changed this designation to "very exceptional." Asperger contended that in the vast majority of cases "work performance can be excellent and with it comes social integration." Moreover, Asperger cautioned that persons with this disorder, who are gifted in various areas and cannot focus on one area necessary for success, often choose the wrong jobs. However, he contended that typically single-mindedness and the sacrifice of other interests do lead to professional success. Asperger's message was that even abnormal personalities are capable of development and adjustment.

I recognize myself and some of my acquaintances in the Asperger's community with reference to certain aspects of the condition Hans Asperger described. Nevertheless, it is necessary to distinguish Asperger's charges.

First of all, Asperger's boys were referred to him for severe misconduct in schools. Admittedly, contemporary American children with Asperger's Syndrome experience teasing and also may become aggressive. That, however, does not result in all of such children being expelled from school. It is very possible that these boys had, in addition to Asperger's Syndrome, what is now diagnosed as Conduct Disorder (CD). Appearing only in children, CD is a precursor to Antisocial Personality Disorder.

Another major difference is a cultural one. Asperger's charges were Austrian boys in the Nazi era. It is very possible that teachers in the Austrian schools were extremely harsh and rigid. This may have greatly exacerbated the already-existing personality problems of children, who in post-war cultures would not be expelled from school. Rather, they would be sent for counseling.

The reader who does not have AS will certainly be enlightened by Hans Asperger's findings; however, readers of this material are not likely to be very many and, thus, the impact on the public consciousness would be negligible. Asperger's major contribution was to show that a child on the autistic spectrum was not doomed to be mute and unproductive, but could become a valuable asset to society.

I next turn to the article by Lorna Wing, who changed the diagnostic label of "autistic psychopathy" to Asperger's Syndrome.

# Lorna Wing, "Asperger syndrome: a clinical account" (1981)

Wing initiated this change because the word psychopathy is equated with sociopathic behavior. Wing's study involved 34 cases of diagnosed Asperger's Syndrome, ranging in age from 5 to 35 years, with 19 having typical features of the syndrome and 15 having many of the features but not the characteristic early history.

Wing initially summarized the findings of Hans Asperger, but she added findings based on her own study. For example, if a person with this syndrome has a strong sex drive, he might try to kiss a stranger older or younger than himself. Consequently, the person might find himself in trouble with the police. Moreover, it was ascertained in Wing's study that the subjects knew many facts but had little comprehension of the meaning of the facts that they learned.

The next section is devoted to "Modifications of Asperger's account." First of all, it was observed that during the first year of life there is a lack of normal interest and pleasure in human company that is normally present from birth. Lack of imaginative play was also found to be a symptom, with the young children engaging in repetitive actions, and excluding other children unless these children follow exactly the patterns the Asperger child has set.

Under this section Wing openly disagreed with Hans Asperger. First, she stated that Asperger's finding that speech always begins prior to walking is inaccurate. Her studies yielded children who walked before they talked and also talked before they walked. With reference to speech, Wing contended that although speech is grammatical, it is pedantic. She found that the content of the speech is impoverished, with the children copying the speech inappropriately from other people or from books. The children were found to know the meanings of obscure words, but not the meanings of every-day words.

Wing stated that Asperger also described people with the syndrome as being capable of originality and creativity in their chosen field. However, she added that their thought processes are limited to a narrow, pedantic, literal chain of reasoning which is nonetheless logical. According to Wing, the unusual quality of the approach of the person with the syndrome is that as the starting point for the logical chain, some aspect of a subject will occur to the person with the syndrome that would not occur to a normal person. Although the result is often inappropriate, it may on occasion offer a new insight. Finally, the special abilities credited to the persons with the syndrome involve, due to a conspicuous lack of common sense, rote memory and not comprehension of the underlying meaning. Wing concluded this section with the admission that most of her subjects suffered from a superimposed psychiatric condition, which biased the study towards persons with severe handicaps.

Wing then addressed "Course and Prognosis." She noted that Hans Asperger had depicted his subjects as having a generally good prognosis, using their special skills

to obtain employment and even to have careers in mathematics and science. However, Wing contended that a significant number of persons with Asperger's Syndrome are average and below average in intelligence (e.g. 20% of her sample). Again, the presence of superimposed psychiatric illnesses affected the prognosis of the subjects of Wing's study. The author admitted that her sample was biased because the subjects had been referred to adult services. Among the psychiatric illnesses Wing described as prevalent among persons with Asperger's Syndrome are depression (including suicide attempts) and schizophrenia.

The next section of Wing's article is entitled "Aetiology and Pathology." Hereunder she discussed briefly the role of heredity and post-natal cerebral damage, but she acknowledged a need for an epidemiological study on these factors. Whereas Asperger could not rely on standardized tests, Wing did utilize such tests and cited good rote memory and poor abstract concepts.

Under the rubric "Epidemiology," Wing noted that the syndrome is much more prevalent in boys than in girls(13:2 and 9:1), and that the girls were superficially more sociable than the boys.

Wing's section on "Differential Diagnosis" included Schizoid Personality, and the author stated that Asperger's Syndrome can definitely be regarded as a form of schizoid personality. The author gave no reason as to why this is the case, but she informed the reader that this will be discussed under "Classification." Schizophrenia may be a differential diagnosis if it is loosely defined. If social withdrawal and speech disorder are the symptoms, then a case could be made for including Asperger's Syndrome under schizophrenia. However, if schizophrenia is strictly defined, it would require that the individual show current or past florid symptoms, such as thought broadcast or feelings that external forces are controlling the person's actions. Wing then acknowledged that only if a person with Asperger's Syndrome had a superimposed schizophrenic illness, could these florid symptoms exist. The author raised the possibility that a hypersensitive person with Asperger's Syndrome, who has been made fun of, could evince behavior that would lead to a diagnosis of a paranoid psychosis.

Wing noted that obsessional neuroses are more commonly diagnosed because persons with Asperger's Syndrome have repetitive interests and activities; however, the person with obsessional neurosis is distressed by the condition, whereas the person with Asperger's Syndrome experiences no distress.

Affective conditions such as depression and manic depression may be diagnosed, based either on the social withdrawal and lack of facial expression or based on excited speech about imaginary, grandiose matters. If an affective condition is superimposed on Asperger's Syndrome, a double diagnosis has to be made based on past history and present state.

Wing found that early childhood autism is the condition most related to Asperger's Syndrome, despite Hans Asperger's contention that they were two separate conditions. Nevertheless, the conditions are more alike than unalike. Some differences do exist, such as the aloofness in an autistic child compared with the inappropriate, one-sided

approaches of the Asperger's Syndrome child. Another difference between the two conditions involves the lack of speech of the autistic child compared with the grammatically correct but inappropriate speech of the Asperger's Syndrome child. Ostensibly the autistic child and adult of low intelligence have abnormal responses to sensory input, while the Asperger's Syndrome child and the autistic adult of normal intelligence do not manifest such responses.

At the end of the "Differential Diagnosis" section, Wing raises the possibility that Asperger's Syndrome and autism are really variants of the same condition.

Under "Classification," the author's main finding, based on a large-scale epidemiological study of all disabled children in one area of London, was that certain problems affecting early child development clustered together in a triad:

- 1. Absence or impairment of two-way social interaction;
- 2. absence or impairment of comprehension and use of language, non-verbal as well as verbal;
- 3. absence or impairment of true, flexible imaginative activity, with the substitution of a narrow range of repetitive, stereotyped pursuits.

According to Wing, each aspect of the triad may occur in varying degrees of severity, and in association with any level of intelligence measured on standardized tests. Furthermore, it is likely that in conditions where the triad occurs, there is a certain impairment of brain functioning required for social interaction, verbal and nonverbal communication, as well as development of imagination. The author advised that grouping and sub-grouping is less useful for classification than for education and management.

Wing opined that perhaps the most important finding is that having a separate classification for Asperger's Syndrome helps to explain the problems of both children and adults to parents, teachers, and work supervisors. The AS diagnosis helps to convince these people that there is a real problem needing careful management and education. The persons in authority often believe that autistics are mute and socially withdrawn.

Under the section "Management and education," Wing stressed the need for regular, organized routine, as well as for finding a balance between letting the child follow his or her bent and requiring conformity. Employees with Asperger's Syndrome do best at jobs with regular routines. They also need supervisors and fellow employees who are sympathetic. The author also suggested living accommodations with a sympathetic landlord. In addition, it is important to furnish parents of young children exhibiting the "triad" with detailed information about the condition. This information will enable the parents to accept and understand the disability. It is also important to provide counseling for the person who has Asperger's Syndrome as well as a superimposed psychiatric condition.

In the Appendix to her text, Wing provided six case histories and qualified that the high achievers mentioned by Asperger were not included.

Case 1 presented a very shy and clumsy young man who had come to the author because he was distressed by his inability to find a female friend due to his shyness. According to Wing, his symptoms were typical of Asperger's Syndrome but complicated by severe depression. According to Wing, these would be core symptoms of Asperger's Syndrome.

Case 2 involved a young man also deemed typical but complicated by depression: He considered himself to be unpleasant and had attempted suicide. He was diagnosed first with schizophrenia and then later with Asperger's Syndrome as well as anxiety.

Case 3 described a young male who had a history of cyanosis after birth. He walked before he could crawl. At the age of five he read at the level of a nine-year-old. The boy, in his early years, was placid and did not react to changes. He was also undemanding. At age six he became fascinated by cars, but he did not include other children in his enacted scenes involving cars. He subsequently made awkward and inappropriate social approaches. His speech was pedantic and his accent different from that of others in his area. He derived his vocabulary from books and television. Although he had become aware of, and sensitive to, social criticism, he could not adapt to the rules governing social interaction. For the most part, Case 3 conforms to what is usually diagnosed as Asperger's Syndrome. Although he was a placid and undemanding child who did not resent change, all his other behaviors fit the syndrome.

Case 4 was rare in the presentation of a twenty-six-year-old female. Her situation was complicated by the trauma of eye surgery before the age of three. Her poor eye-sight at the time of her interview with Wing did not prevent her from reading, writing, and typing. Otherwise, this young woman's development conformed to that of persons with Asperger's Syndrome. Initially withdrawn after the eye surgery, the child began to be social towards members of her family. However, she still was not social to children of her own age. There was no normal play or pretend play. Her main interests were drawing, reading, and doll collecting. She would arrange the dolls in rows, and the order could not be disturbed. At school she excelled in history and geography, but she would not work in any subject that did not interest her. The other children accepted her despite regarding her as odd. Her speech was full of long quotations and irrelevant comments. She was poor at practical tasks. Her work history as a copy typist was initially gratifying, but she made no friends. When her workload became more pressured, she left the job and remained unemployed for three years. In addition, the young woman had childish temper tantrums when she did not get her way.

Case 5 dealt with a young adult male who had features of Asperger's Syndrome. He was also mentally retarded and unable to live independently. Walking and speech were delayed. He learned to read at age five and a half and knew unusual words, but was stymied by everyday vocabulary such as "yesterday." The young man was not aloof, but rather gentle and passive. He was content to stand on the sidelines in social situations. He attended a school for retarded children and was later placed in a training center for retarded adults. His special interests were music and cars, and he displayed a remarkable ability to identify any make of a car. Although he read well in advance

of his years, intelligence tests indicated that he was mildly retarded in some areas and severely retarded in others.

Case 6 offers the strongest support for the proposition that Asperger's Syndrome and autism are at different points on the same spectrum. Prior to age three, the subject boy of Case 6 was socially aloof and ran in circles for hours, screaming at any attempt to stop him. He would also sit for hours and draw salt and pepper pots. He never had pretend play, but was deeply attached to a toy panda to which he talked. However, when he reached five years of age his speech and social contact improved markedly. He attended a special school until he was eleven and was subsequently transferred to a normal comprehensive school. His intelligence was normal. He preferred the company of adults to that of his peers. His speech was naïve and immature and revolved around his special interests. He learned to avoid making inappropriate remarks about others' appearance, but he continued to ask repetitive questions. He was often teased by classmates. Due to his lack of coordination, he was not chosen by other children for team sports. His special interests were in maps and road signs, and he displayed a remarkable memory for routes. He had a normal intelligence, but displayed a poor comprehension of abstract ideas. He was deemed to be appealing but vulnerable to the problems of everyday life. Case 6, from infancy to age five, appeared to be an example of classic autism. Yet he later developed into a boy who displayed most of the symptoms of Asperger's Syndrome.

Among Wing's most notable contributions to autistic spectrum scholarship is the term "Asperger's Syndrome," which rendered the diagnosis comprehensible and often bearable to countless families with Asperger's children. Thus, her research had a positive impact on the public consciousness despite the fact that Wing's scholarship is accessible only to a limited segment of the public.

The next voice to speak on Asperger's Syndrome is that of Tony Attwood, whose book offers not only the findings of a qualified professional, but also strategies for treating and managing Asperger's Syndrome.

# Tony Attwood, Asperger Syndrome (1998)

Atwood divides his slim volume into eight chapters: Diagnosis, Social Behavior; Language; Interests and Routines; Motor Clumsiness; Sensory Sensitivity; and Frequently Asked Questions. I will discuss parts of chapters that I feel will resonate most with the reader.

Chapter 1, Diagnosis, offers what the original Asperger's scholars could not provide: The Australian Scale for Asperger's Syndrome (ASAS). Briefly described, the rating scale covers Social and Emotional Abilities, Communication Skills, Cognitive Skills, Specific Interests, Movement Skills, and Other Characteristics (such as Sensory Issues). Attwood's ensuing Diagnostic Assessment addresses formal tests/range of interests, as well as reports from parents, teachers, and therapists. This procedure also engenders

situations to elicit specific behaviors. Language skills, movement skills, and learning abilities, as well as special interests are also evaluated. Attwood noted that neither Hans Asperger nor Lorna Wing had explicitly stated criteria for AS. Finally, Attwood outlined the six pathways to a diagnosis of AS: Early autism in childhood; recognition of features when enrolled at school; atypical expression of another syndrome (such as ADHD); diagnosis of a relative with AS; secondary psychiatric disorder (such as depression); residual AS in an adult who was referred based on a diagnosis of atypical schizophrenia or alcoholism. Here Attwood noted that in rare instances a special interest may bring the person with AS into contact with the criminal justice system, upon which a forensic psychiatry service will diagnose the person.

Chapter 2 addresses a core issue in Asperger's Syndrome: Social Behavior. Attwood informed the reader that social impairment may be measured by various criteria such as those set forth in the DSM IV of 1994 and by the World Health Organization. According to Attwood, play with other children is a criterion. Specifically, some young children are content to be alone or with adults, but the older children seek contact and are often rebuffed. AS children may be oblivious to codes of conduct or be rigid enforcers of these codes. Attwood listed ways in which deficits in social skills may be remedied: Using short stories to illustrate inappropriate behavior; inviting the AS child to play while observing conduct and correcting it; enrolling the child in clubs; and having the AS child or teen participate in Social Skills Groups. Atwood admonished that AS people tend to accept an abusive relationship rather than suffer loneliness. Although it is often believed that AS people have no deep feelings, the author cited an example of a young man who, after a reciprocal romantic relationship had ended, said that life was easier when he did not care.

Attwood addressed head on the issue of lack of empathy under the rubric of Emotions. This feature does not mean that the AS person is incapable of caring for others. Rather, the person is confused by the emotions of others and has difficulty expressing his or her own emotions. The suggested strategy is to show pictures of happy and sad faces, to ask what might be said to make the sad person feel better, and to show a gauge of an emotion from irritated to enraged. According to Attwood, the AS person is not callous when making shocking statements, but rather is trying to understand how to influence and predict feelings of another person. Attwood used as an example a person with AS who had a Ph.D. in physics and was working on a mathematical formula to predict behavior. The author noted that distress shown as giggling may mean not that the child is amused, but rather that the child finds amusing some word or words rather than the situation.

I note that while attending classes at the John Jay College of Criminal Justice I heard lectures and read books explaining the lack of empathy in persons diagnosed with psychopathy or Anti-Social Personality Disorder. An example of such material is the text edited by Thomas Millon and his colleagues, entitled *Psychopathy, Antisocial, Criminal, and Violent Behavior*. Based on extensive reading and course work, I believe

that the lack of empathy in AS people does not accord with the behavior of cold-blooded criminals.

Also under Emotions, Attwood listed a stoic ability to bear physical pain. People with AS, according to Attwood, tend to have body language perceived as aloof or aggressive. This may be remedied by videos with role-play. Finally, people with AS tend to have difficulty verbally expressing their emotions and may fare better expressing feelings in writing.

I next discuss Chapter 4, Interests and Routines. Under the rubric of Interests, Attwood first stated that such interests are stable over time and that two characteristics are not sufficiently addressed in the literature: That the fascination for the special interest dominates the person's time and conversation; that there is an imposition of routines which must be completed. In childhood the fascination is with collections of objects, whereas in adolescence and adulthood the fascination is with topics. Furthermore, the preoccupation with a topic may disregard safety by, for example, causing an explosion. The AS person may pretend to be another person or an animal. Finally, during or following adolescence, the AS person may develop an infatuation rather than an intellectual fascination.

Under the rubric of Routines, Attwood distinguished the AS routine from that of the person with a compulsive disorder. The AS person enjoys the routine and does not resist it. Attwood contended that the lack of completion of an activity (i.e. not following the routine) causes the AS person distress and anxiety because the routine ensures consistency and order in a chaotic life. For the person with a compulsive disorder, following the routine causes distress.

Returning to the special interests of the AS person, Attwood emphasized that the activities are solitary and idiosyncratic. Whereas children may be given only controlled access to these activities, in adults such an interest may lead to a productive career such as in law or *academe*. According to Attwood, the AS person uses these interests to facilitate conversation, for relaxation, for enjoyment, and to exhibit their intelligence by often using big words. The author noted that AS persons fear being considered stupid.

Chapter 6, Cognition, contains a distinction between autistics and persons with AS. Attwood stated that the autistic thinks in visual terms whereas the person with AS thinks in verbal terms. Because conventional education utilizes verbal learning, people with autism often encounter problems. According to Attwood, Einstein and Bill Gates could have an Asperger's diagnosis.

In Chapter 7, Sensory Sensitivity, Attwood addressed a feature of AS that is not listed among the symptoms in the DMS-IV. There is evidence to suggest that 40% of children with AS may have some abnormality of sensory sensitivity which may diminish with age or continue through their lives. Attwood listed the various sensitivities and noted that the most common involve sound and touch.

Regarding sound sensitivity, sudden unexpected noise, high-pitched continuous noise, confusing multiple sounds, and barking dogs appear to be the most common.

Attwood explained that tactile sensitivity relates often to touching parts of one's body. Temple Grandin dislikes being hugged. Another source of tactile sensitivity is the feeling of clothing on one's body.

Taste and texture of food are sometimes issues for people with AS. Some of us cannot bear it when foods are mixed (for example noodles and vegetables). Visual sensitivity is rare, but bright lights may be blinding.

According to Attwood, people with AS have sensitivities to various smells, such as perfume or cleaning fluid. I myself become nauseated by the smell of cigar smoke.

Attwood warned that the hyposensitivity and stoic tolerance for pain and temperature can make it impossible to avert dangers such as extreme heat or illness. Michael John Carley, for example, was able to tolerate the discomfort of getting sober without being in a program.

According to Attwood, synaesthesia is rare and occurs when a person, with or without AS, has sensation in one sensory system which results in sensation in another system (such as hearing a certain sound resulting in seeing a certain color). My Beacon Daniel Tammet has this condition.

Attwood concluded this chapter with some strategies reminiscent of Zosia Zaks's strategies for people with autism. Among the suggestions are that the person with sound sensitivity should avoid certain sounds or wear earplugs. The person with tactile sensitivity should buy duplicates of clothing articles that are tolerable, while the person with visual sensitivity should wear sunglasses.

In Chapter 8, Frequently Asked Questions, Attwood responded to questions concerning Asperger's Syndrome. I shall cite some of the questions and Attwood's replies.

- 1. Can Asperger's Syndrome occur with another disorder? Attwood listed a few medical disorders, including cerebral palsy, Tourette Syndrome, and tuberous sclerosis. No psychiatric conditions were mentioned in this response.
- 2. What is the difference between a syndrome and the normal range of abilities and personality? Attwood replied that some children have a "ghosting" or "shadow" of the condition, but that Asperger children have characteristics that are qualitatively different and beyond the normal range, with a distinct pattern.
- 3. Could the pattern be secondary to a language disorder? Attwood stated that some children with language disorders may evince qualities that are superficially similar to AS, but the child with AS has more severe and complex social impairments. Semantic Pragmatic Language Disorder, however, can duplicate many of the language features of AS and shade into a milder form of AS.
- 4. Could it be a form of schizophrenia? According to Attwood, recent studies showed that at most 5% of AS patients developed schizophrenia. Attwood acknowledged that the speech of a person with AS may resemble a schizophrenic's speech, and that due to misinterpreting others' actions, a person with AS may seem paranoid.
- 5. What is the difference between High Functioning Autism and Asperger's Syndrome? Here Attwood emphasized that the two conditions are really the same, and that the only difference would be that the person with HFA would have had an early

diagnosis of autism whereas the person with AS would not. Moreover, some agencies will provide care for persons with autism, but Asperger's would not be covered because it is relatively new.

- 6. Do girls have a different expression of the syndrome? Attwood first stated that for every 10 boys with AS , there is one girl. The author explained that girls tend to be able to play with others by delayed imitation, and that they are considered immature rather than odd.
- 7. How can you reduce the person's level of anxiety? Attwood suggested special accommodations at school (such as a substitution for play period if it is too stressful) and also Cognitive Behavior Therapy and cognitive skills training.
- 8. Is the person likely to become depressed? Attwood replied that there is a greater risk of depression, with up to 15% of persons with AS having this affective disorder. Conventional medication as well as cognitive training to deal with the core issues of AS are needed.
- 9. How do you control the person's temper and anger? Attwood noted that children with AS provoke either maternal or predatory instincts in others. The AS child may suppress his or her rage at being teased by others and find relief in aggression against a person or property. A good way of coping with temper is to list warning signs leading up to the person's temper and to create a list of ways to reduce the person's stress. Attwood acknowledged that there are rare cases where the temper arises without warning and may be due to neurological factors such as complex partial seizures.
- 10. What are the changes we can expect during adolescence? First of all, Attwood explained that the physical changes occurring with puberty may be confusing to AS teenagers. The AS teenager is less likely to seek romantic relationships and tends to focus on friendships and high grades. Finally, the AS teen often develops sexual attraction and strong attachment to someone later than his or her peers, and adolescent qualities continue well into the twenties.
- 11. Can the person develop normal relationships? Attwood replied that not all people with AS remain celibate, some finding partners with like interests. Attwood noted that Temple Grandin chose celibacy to avoid complicated social situations. If the person with AS has a partner who does not have the syndrome, that partner may be very nurturing and value the loyalty and honesty of the AS partner. However, couples counseling may be needed when problems arise due to AS issues. Since the range of normal is so wide, Attwood opined that normal relationships are possible.
- 12. Are people with Asperger's more likely to be involved in criminal activities? Attwood stated that the incidence of violent offenses is remarkably low; however, he acknowledged that some people with AS may commit crimes due to the nature of their special interests, sensory sensitivity, or moral code. Parents of children with AS need not fear that their children will engage in criminal activity because such instances are rare.

- 13. What resources are needed? Attwood emphasized the need for access to professional expertise and to support in the classroom, as well as for contact with local support groups and access to web sites.
- 14. What are the advantages of using the term Asperger's Syndrome? Attwood emphasized that the term provides relief to parents when they know the condition is not their fault because it is neurobiological in nature. Autism is associated in most people's minds with a low level of functioning, whereas Asperger's Syndrome can be explained to professionals treating depression and anxiety as a neurological condition affecting social behavior.
- 15. How do you share the news? According to Attwood, the child should be told when he or she has the coping skills to handle the news. In school, sharing should be on a need-to-know basis If the diagnosis is shared with other children, it should be done in a way that inspires them to want to help the AS child.
- 16. What would be a suitable career? Atwood suggested as options engineering, law-enforcement professions, and self- employment.
- 17. What are the long-term outcomes? According to Attwood, the following factors may contribute to successful outcomes:
  - -A mentor (parent or teacher) who provides guidance and inspiration;
  - -a partner who provides support, affection and commitment;
  - -success in a profession which utilizes the person's strengths;
- -coming to terms with one's strengths and deficits and no longer wanting to be someone else;
  - -a natural recovery which may take many years.

I have dealt in detail with this final chapter in Attwood's book because it summarizes the most important issues in the lives of people who have AS or who have a close relationship with a person with AS. Tony Attwood has both clinical experience and hands-on strategies that can benefit those persons who live with AS, such as parents and teachers. Moreover, the book is enlightening for those persons who live in AS – namely the Asperger's Syndrome community.

Attwood's informative and accessible text had a very positive impact on the consciousness of persons who have Asperger's Syndrome or High Functioning Autism. It also impacted on those who treat, teach, and otherwise interact with persons on the spectrum. For example, it was praised in the *Journal of Child Psychology and Psychiatry*. Dr. Temple Grandin recommended Attwood's text for those on the autistic spectrum as well as for anyone who works with persons with AS or High Functioning Autism. The book was also favorably reviewed in the mainstream newspapers *The New York Times* and the *Los Angeles Times*.

#### Ami Klin, Fred R. Volkmar, and Sara S. Sparrow, Asperger Syndrome (2000)

This comprehensive volume, edited by Klin, Volkmar and Sparrow, contains extensive contributions concerning Behavioral Aspects, Family Genetics and Neurobiological Aspects, Related Diagnostic Constructs, Assessment, Treatment, and Intervention, as well as Perspectives on Research and Clinical Practice, and Parent Essays. There can be no impact on the consciousness of the general public because the essays contained in this volume are intended predominantly for persons with a mental health background.

I will first address "Diagnostic Issues in Asperger Syndrome" by Volkmar and Klin. This will be followed by a discussion of "Nonverbal Learning Disabilities" by Rourke and Tsatanis. The final discussion of essays in the book will cover "Schizoid Personality in Childhood and Asperger Syndrome" by Wolff.

## Fred R. Volkmar and Ami Klin, "Diagnostic Issues in Asperger Syndrome"

The authors first addressed a critical question: Whether AS differs in some important way, or ways, from autism, PDD-NOS and other conditions. The condition required is that AS can be distinguished from autism in a reliable and empirical fashion. The authors stressed that the condition must be truly external, avoiding circular reasoning and, if discovered, must be the product of factors independent of the original diagnosis assignment. Further complicating factors pointed out by the authors arise because alternative diagnostic concepts such as schizoid disorder or semantic- pragmatic disorder have been proposed and share some basic similarities with AS.

The authors also emphasized that various approaches to diagnosis of AS can be used, such as Hans Asperger's findings, Lorna Wing's modifications, as well as the information contained in the *DSM-IV*.

Then the validity of Asperger's Syndrome as a diagnostic concept apart from autism is discussed. Here, neurobiological differences, course and outcome, co-morbidity, family history, and treatment are addressed. The following conclusions are reached by the authors:

- 1. To establish better diagnosis of AS, and the validity of the diagnostic concept, the following must occur: Circularity must be avoided; specific and clear operational definitions must be utilized; there must be a move toward standard diagnostic procedures; premature closure of any aspect of the research on AS and related conditions must be avoided; and there must be a consideration of overlap with conditions other than autism.
  - 2. Dependent measures, which are independent of the diagnosis, must be used

- 3. The effort to validate Asperger's Syndrome as a diagnostic concept should not be bound to preconceived, non-empirical ideas as to whether AS is the same or different from autism.
- 4. If we say that AS and autism are on a continuum, the discussion should include other conditions as well that may share areas of the disability.
- 5. The repeated suggestion that the nature of the social deficit may take different forms in AS and HFA is important. Researchers have found that the AS individual desires social interactions but is unable to engage in them, whereas there is social avoidance in autism. Moreover, in AS there is eccentric, one-sided interactions.
- 6. The ultimate interest, which is the entitlement to services, is unlikely to be served based on loose diagnostic considerations.
  - 7. Diagnostic issues are important in the context of treatment and outcome.

Before discussing the next contribution, I draw the reader's attention to the demand for precision and open-mindedness found in the above-summarized article.

# Byron P. Rourke and Katherine D. Tsatanis, "Nonverbal Learning Disabilities (NLD) and Asperger's Syndrome"

Among the characteristics of Nonverbal Learning Disability there is extreme difficulty in adapting to novel and otherwise complex situations over time, and adapting to it by overreliance on prosaic rote. The consequences are frequently inappropriate behavior in such situations. There is also difficulty in nonverbal problem solving, as well as a deficient capacity to accept beneficial positive and negative feedback in such complex situations. Rote verbal capacity is well developed, and there is much verbosity of a repetitive and rote nature. There is also marked deficiency in mechanical matters and arithmetic, as compared to the proficiencies in reading and spelling. This disability is also characterized by significant deficits in social perception, social judgment, and social interaction skills. In preschool years there is a tendency to hyperactivity. As the person grows older, there is likely to be withdrawal and even social isolation. Unlike other persons with learning disabilities, NLD persons have psychosocial and adaptive difficulties.

There is extensive research comparing NLD to Asperger's Syndrome and High Functioning Autism. Whereas there is support for a link between NLD and AS, this concordance did not exist between NLD and HFA. Individuals with AS and NLD have the same difficulties in social interaction, particularly of a nonverbal type. In both individuals with AS and NLD there is an overreliance on language to learn about themselves and the external world. The correspondence in neuropsychological profiles of NLD and AS indicate a distinction between AS and HFA.

The authors concluded that there is strong evidence that individuals with AS, but not with HFA, present with virtually all the characteristics of NLD. For this reason, the authors find that there is a basis to draw a distinction between AS and HFA.

#### Sula Wolff, "Schizoid Personality in Childhood and Asperger Syndrome"

Children seen in a psychiatric practice in the 1960s were followed from childhood into adulthood. The children had been diagnosed with Schizoid Personality Disorder, which corresponds to Type A of Personality Disorders (Odd, Eccentric) in the *DSM-IV*. When Uta Frith's translation of Hans Asperger's 1944 paper appeared in 1991, Wolff and her colleagues realized that their group of children corresponded to the children Asperger had described, except for the fact that girls had been included in Wolff's study.

Wolff's subject children also resembled children given the diagnosis of Schizotypal Personality Disorder (also Type A, Odd, Eccentric), but they were less socially impaired in both childhood and adulthood than groups of children diagnosed with AS.

Wolff's group of children had common child psychiatric symptoms, but had no adverse background to explain the symptoms; nor did they respond to psychotherapy. These children did not conform to social demands, especially in a school setting. When pressed to conform, they reacted with fits of weeping or rage and aggression.

According to Wolff, there are six core features of schizoid children

- 1. Solitariness
- 2. Lack of empathy and emotional detachment
- 3. Increased sensitivity at times and paranoid ideation
- 4. Single-minded pursuit of special interests
- 5. Unusual or odd style of communication
- 6. Unusual fantasy life

Wolff found that the children's parents often shared their children's personality traits. Moreover, Wolff observed that although some children were generally shy and uncommunicative, solitariness was not at odds with being outgoing. Specifically, there was superficial sociability, verbosity, and tactless verbal communication without regard for the needs and interests of other children.

Next, the author turned to prognostic validation studies and found that 75% of schizoid men and women also fit the diagnosis of Schizotypal in *DSM-III*. Moreover, there was a finding that schizoid children and adults were far less impaired in their psychosocial functioning than people being given the current diagnosis of AS or autism. Finally, the overall outcome for the schizoid children was found to be reasonably good.

With regard to schizotypal children, Wolff stated that they resembled both Asperger's and Wolff's schizoid children. Specifically, the schizotypal children manifested

the core features of social isolation, social anxiety, magical thinking, bizarre preoccupations, poor rapport, and odd speech.

The author also raised the possibility that the schizotypal subjects may have had a variant of adult schizophrenia or a mild form of autism. Moreover, a link with schizophrenia was found to exist because more children than expected developed schizophrenia later in life. This finding may indicate that the Type A Personality Disorders are equivalent to Schizophrenia Spectrum Disorders. However, most of the schizoid children remained free of serious mental illness. Despite the possible link to this thought disorder, the risk of developing schizophrenia was small.

Among the final conclusions Wolff drew are the following:

- 1. The current DSM-IV diagnosis identifies only the most severely impaired among Asperger's groups;
- 2. the more mildly affected (and even gifted) children and adults need the nature of their basic difficulties recognized as constitutionally determined so that their symptoms are not attributed to poor upbringing;
- 3. co-morbidity may obscure the diagnosis of specific developmental disorders, which require special education provisions;
  - 4. associated conduct and other disorders require realistic treatment approaches;
  - 5. care should be devoted to fostering the children's special interests and gifts;
- 6. it is difficult to reconcile the fact that Schizoid Personality Disorder in childhood appears to lie at one end of the autistic spectrum, which merges with normal personality variations but is related to the schizophrenia spectrum;
- 7. schizophrenia and autism are recognized as neuro-developmental disorders with a genetic basis;
- 8. family history studies on less severely affected schizoid children would establish whether genetic overlap exists between Schizoid Personality Disorder, Asperger Syndrome, and autistic disorder on the one hand and schizophrenia on the other hand.

Although the volume edited by Frith in 1991 included contributions by authors other than Asperger, the volume edited by Klin, Volkmar and Sparrow in 2000 is more contemporary as to the research contributions contained therein. I also selected this volume because it dramatically illustrates how diverse the findings and views on AS are. The various authors all made cogent arguments to support their views.

The next work I will discuss is a psychology journal article, in which the authors argue that there is no research to support the DSM-IV diagnosis of AS.

### Susan Dickerson Mayes, et al, "Does *DSM-IV* Asperger's Disorder Exist?" (2001)

According to Dickerson Mayes and her colleagues, Hans Asperger's narrative description and case presentations are entirely consistent with the DSM-IV description

of Autistic Disorder (impairment in social interaction, impairment in communication, restrictive and repetitive behaviors and interests, associated features such as unusual sensory responses, as well as above to below normal intelligence). Asperger's subjects displayed limitation of social relationships (a fundamental disorder of autistic individuals), abnormalities in language, special interests and abnormal fixations, unusual sensory responses, and intelligence from highly original genius to mentally retarded individuals.

Pre DSM-IV, proponents of an AS diagnosis proposed the following differences between AS and autism: Better social and language abilities; more unusual and conspicuous interests and preoccupations; fewer stereotypies; fewer or no sensory abnormalities; higher, though not necessarily normal, IQ; and greater lack of motor coordination. In essence, these proponents of the AS diagnosis found that, with the exception of motor coordination, persons with Asperger's Syndrome were less impaired than persons with autism.

Prior to the publication of the *DSM-IV* in 1994, there was lack of consensus among the diagnosticians. Thus, differing relationships between AS and autism were proposed as follows: AS to be on a continuum with autism; AS to not be a separate diagnostic entity, but on the autistic spectrum; AS to be a mild variant of autism; AS to be the equivalent of High Functioning Autism (HFA); AS to be a mild form of HFA.

In the *DSM-IV*, under AS, Dickerson and associates pointed out the following: The diagnosis did not specify that individuals with AS were less socially impaired than individuals with autism; no communication impairment was listed under AS; two new criteria were added (no significant cognitive delay and no significant language delay).

Dickerson and colleagues added that post-DSM-IV there was disagreement with the diagnosis, with some authors contending that individuals with AS are less severely affected than those with autism, and that individuals with AS have better social and language skills than individuals with autism. Other authors insisted that a person with AS may have language abnormalities and may be in the mentally retarded range, and gross motor in-coordination was disputed.

The authors explained that all these disputed findings regarding AS prove that there is a lack of research to support the *DSM-IV* AS diagnosis and added that in 1995 among 68 pre-school children diagnosed with Pervasive Developmental Disorder (including 21 with a diagnosis of AS), only one child met the criteria for AS in the *DSM-IV*, proving that it was virtually impossible to make a diagnosis of AS based on the *DSM-IV*. Moreover, in 1997 there was a study that proved that Asperger's original four cases met the criteria for autism, and not for Asperger's Syndrome according to the *DSM-IV*. Tony Attwood is quoted by the authors as stating in 1998 that AS is a form of high functioning autism.

Dickerson and associates conducted a study with 157 children diagnosed with AS or with autism. The results were a 100% diagnostic agreement between the psychologists conducting the evaluations and the child psychiatrists who independently reviewed each child's chart. All 157 children with normal IQ's met the criteria for autistic disor-

der in the *DSM-IV*, whereas none met the *DSM-IV* criteria for AS. All the subject children had delays before the age of three, or abnormal functioning in social interaction, communication, and imaginative play. All the children displayed social impairment and communication impairment, resulting in a diagnosis for autism, and not for AS.

The authors prefaced their conclusions with the statement that children with mild symptoms of autism and with high IQ's are variously referred to by different clinicians as having autism, High Functioning Autism, Mild Autism, Asperger's Syndrome, Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS), or Autistic Features. This creates enormous confusion for parents and professionals and implies that these diagnoses are separate and distinct disorders, differing in clinically meaningful ways. This may, in fact, not be the case and has not been proven empirically.

The separate diagnoses for autism and Asperger's Syndrome may indeed engender confusion among mental health professionals and also in the mind of a person living with this disorder. Due to the fact that the article engenders confusion rather than clarity, its impact on the public consciousness is probably more negative than positive.

On the other hand, in the next article to be discussed, the author differentiates clearly between the diagnoses of AS and autism.

# Richard Perry, "Early Diagnosis of Asperger's Disorder: Lessons From a Large Clinical Practice "(2004)

Perry, for over twenty-five years, in both hospitals and private practice, has evaluated and treated hundreds of children, adolescents, and adults. According to Perry, presenting problems in AS are of a social or behavioral nature, whereas in autism there is usually abnormal language development. In some cases children in their early years meet most of the criteria for autism or PDD NOS, but later the clinical pictures develop into AS.

Problems and behaviors manifested by AS children overlap with those of children with other psychiatric disorders. Among the symptoms Perry listed are inattention, impulsivity, sensory issues, learning problems, oppositional behavior, preoccupations similar to OCD, and affective storms.

Advising on the requirements for a valid diagnosis, Perry emphasized the need to take a detailed history from the parent or guardian, and also to gather additional information from teachers and other professionals. It is crucial to ascertain how the child relates to peers. After the case history has been taken, a clinical interview with the child is needed. The interviewer must look for other symptoms of AS such as inappropriate (often flat) affect, poor eye contact, prosody (unusual way of speaking), inability to engage in a give-and- take conversation, and intense preoccupations with their interests. Perry noted that since AS children generally relate better to adults

than to peers, there may well be children who do not show any AS symptoms during the one-on-one interview. The child should be observed interacting with parents for at least several minutes. Overly demanding, self-centered behaviors should be looked for.

Perry stated that many (approximately 50%) children with AS who come to his practice are mistakenly diagnosed with ADHD. The major difference between AS and ADHD is that in AS children interests are more limited in number, and there is a greater degree of obsession with certain interests as well as resistance to transitioning to other activities. Moreover, the degree of inattention varies in ADHD, depending on the activity, and there is a lack of focus. In AS there is focus on books and media while collecting information on circumscribed interests.

Next, perseverations, preoccupations, fixations, and other OCD-like behaviors are discussed. First of all, there is no clear boundary between typical childhood interests and intense circumscribed interests typical of AS. It is precisely these intense interests that are often the first sign of AS in children at an early age. Timing, intensity and nature of interests reflect the presence of AS. Among the areas of intense interests typical of AS are cars, maps, computer games, statistics, and animated film characters. AS children tend to engage in long monologues, forcing their interests on others during play or in communication. This behavior often alienates peers, and AS children tend to prefer to be with younger children whom they can teach.

Perry added that AS children reject team sports. It should be noted that some repetitive behaviors associated with autism are also present in AS children; these behaviors include hand flapping and spinning in early years, which may recur in later years in times of stress or loneliness.

In Perry's article, the subject of aggression and affective lability is discussed. AS children are described as follows: Demanding, with poor frustration tolerance; impulsive (like ADHD); as toddlers grabbing other children's toys and refusing to share their own toys; having boundary issues, such as inappropriately touching others or standing too close. Perry attributed this to an inborn deficit in appreciating the needs and perspectives of others, resulting in lack of empathy. When older, the AS person makes demands on parents. When frustrated, the AS person may menace or hit the parent, particularly the mother. Persons with AS may be misdiagnosed as having an affective disorder due to the diagnostician's failure to comprehend that the person's lack of appreciation of other people's rights contributes to aggressive behavior.

Under the rubric of Sensory Issues, Language and Learning Disorders, Perry first addressed sensory issues in AS, noting that among them are smells, loud sounds, and the feel of clothes. Persons with AS may touch others due to a need for tactile stimulation or lack of physical coordination, indicating possible problems with sensory integration.

With regard to language and learning disorders, Perry found that a prior diagnosis with Pragmatic Semantic Language Disorder or a Nonverbal Learning disorder due to social problems may indicate an associated AS diagnosis. The author noted that persons with AS often have a remarkable remote memory for both important and trivial events, and that verbal IQ is usually much higher than performance IQ.

The last area addressed by Perry in his article is under the rubric of Anxiety and Affect Recognition. Anxiety in social situations, due to the lack of safety inherent in solitude, may be alleviated with help in developing social skills. In addition, AS children are poor at describing their own affective states as well as at judging the affective states of others, indicative of poor appreciation of social cues.

The inability to discern what others are thinking or feeling is often referred to as lack of empathy and hence confused with inability to feel sympathy or compassion. Perry noted that this AS deficit has also been described as "mind blindness."

The major message Perry sought to impart in his article is that early diagnosis of AS is crucial, and that there is a need for child and adolescent psychiatry fellowships to ensure that trainees are properly trained in diagnosing and treating AS. The author warned that delayed diagnosis may have disastrous effects on both the mental state and academic progress of the child with AS. Perry's contribution should have both an enlightening and positive impact on his readership, which will be limited to professionals and most likely to family members of individuals with AS. However, the consciousness of the general public will not be impacted.

Before concluding the section on the findings of psychiatrists and psychologists, I think it highly relevant to discuss a very recent work on AS by a noted mental health professional. The author also offers the most current findings in the area of CBT (Cognitive Behavioral Therapy).

#### Valerie L. Gaus, Cognitive-Behavioral Therapy for Adult Asperger Syndrome (2007)

Gaus's text begins with an explanation of AS and a description of Cognitive Behavioral Therapy which she has found to be beneficial for people with our condition.

First, Gaus enumerated the myths surrounding persons with AS: We are always aloof and uninterested in others; we have no relationships; we do not make eye contact; we lack empathy for others; and we are intellectual geniuses. The author disputed these myths by citing the amazement of people who discover that a person with AS can be outgoing, can be married with children, can look one directly in the eye, and can be caring and concerned for others. Finally, Gaus clarified that some people with AS are intellectually superior while others are not, which does not preclude an AS diagnosis. With reference to lack of empathy, Gaus explained that this is rooted in impaired ability to show cognitive shifting with the rapid pace required by most social situations. Based on anecdotes, Gaus stated that if people with AS are given appropriate information and sufficient time to process it, they can show as much concern and empathy as the rest of the population.

According to Gaus, people with AS have strengths and assets such as creativity, an unconventional view of the world, honesty, a sense of humor, responsiveness to structure, and a willingness to observe and evaluate ourselves.

Based on her experience treating people with AS, Gaus admonished that core problems in AS patients are often pathways to mental health problems such as processing information about others and self as well as non-social information, social skills deficits, and problems in self- management. The social consequences of these core problems lead to the person being ignored, rejected, and often ridiculed. These consequences frequently result in poor social support, causing anxiety and depression. The daily living consequences lead to hassles, stressful events, and chronic stress, resulting in anxiety and depression.

Gaus also addressed major sensory issues associated with AS. Tactile sensitivity entails discomfort from contact with certain things or persons, which would not disturb people who do not have AS. This sensitivity can lead to drastic, or even dangerous measures, to avoid such contact. Vestibular sensitivity involves balance and low tolerance for movement. Visual sensitivity entails low tolerance for lights or certain patterns. Auditory sensitivity involves a severe reaction to certain sounds (sudden, or high-pitched, or noisy settings such as parties). Gustatory sensitivity entails strong reactions to certain foods and olfactory sensitivity can mean a strong negative reaction to some smells, or possibly no reaction to some smells.

When Gaus discussed Cognitive Behavioral Therapy(CBT), she first explained that a *schema* is a cognitive structure that guides and organizes perceptions of events and experiences, specifically regarding others, self, world, and future. Then the author enumerated the vulnerabilities of an AS patient with regard to CBT. With reference to cognitions, there are social cognition deficits and cognitive rigidity. With reference to behaviors, there are social skills deficits and poor self-management. As to events, there are multiple negative life events in all stages of development. With regard to *schemas*, there is a risk for developing even more maladaptive *schemas*.

Cognitive distortions to be remedied by CBT include the following: All-or-nothing thinking; catastrophizing; "should" statements; personalization (i.e. attributing the behavior of others to oneself); labeling (e.g. "loser"); mental filtering which blocks out the positive while letting in the negative; mindreading (believing one can know the thoughts of others without any evidence to support the belief); emotional reasoning (i.e. "if I feel it, it is true"); and – finally -overgeneralization.

Gaus explained how she tailored CBT for persons with AS. The patient with AS must learn to re-conceptualize social interaction and become better able to "read" behavior of others and to understand "codes of conduct." The patient with AS must learn to monitor his or her own behavior, and also to monitor responses to other people and situations. Moreover, the patient with AS must learn to recognize and adjust maladaptive patterns of information processing that contribute to stress, anxiety, and depression.

Despite success with CBT, Gaus acknowledged that obstacles to treatment exist, which should be recognized and addressed. Social interaction difficulties entail behavioral, communication, and cognitive issues. Persons with executive function problems are unable to cope with the tasks of daily living. Low motivation and rejection of the cognitive model will make treatment very problematic and possibly ineffective. Family issues and financial problems may also interfere with treatment. Substance abuse, untreated health problems (e.g. diabetes), multiple medications without rationale, as well as lack of cooperation from other health care providers are all serious obstacles. The patient's isolation and lack of support may also prove an obstacle to treatment with CBT.

Gaus provides not only insight into AS, but also explains a method that has proved to be effective in many cases. The language of her text is accessible. Moreover, she offers hope to both patients and family members, whose lives are often fraught with hopelessness. Although Gaus's book won't impact the consciousness of the general public, it will favorably impact her target audience: Those of us with Asperger's Syndrome and the persons with whom we interact.

The preceding section covering the findings of psychiatrists and psychologists on Asperger's Syndrome is, clearly, is not all-inclusive. My intention was to show how diverse the views on Asperger's Syndrome are. They range from regarding AS as a disorder separate from autism (or any other developmental disorder), to arguing against the very existence of AS. The books and articles I selected span six decades. Who or what we are will, in the last analysis, not be determinative of how our lives will progress. Rather, the treatment we receive from all the people and organizations we encounter, our own ability to accept constructive criticism, and pure luck will determine the course of our lives.

Before introducing the topic of the alleged criminal predisposition found in persons with AS, I am drawing the reader's attention to a recent article announcing that the forthcoming 2012 DSM-V (Diagnostic and Statistical Manual of Mental Disorders) will be "folding" both AS and Pervasive Developmental Disorder Not Otherwise Specified (P.D.D. –N.O.S.) into one broad diagnosis – Autism Spectrum Disorder. I have, therefore, added a discussion of an article addressing the issue of eliminating Asperger's Syndrome from the 2012 DSM-V.

## Claudia Wallis, "A Powerful Identity, a Vanishing Diagnosis" (2009)

The author of this *New York Times* article cited comments from noted psychiatrists, as well as from the author Dr. Temple Grandin, and other persons in the autistic community.

The psychiatrists state their support for the new edition with the argument that the AS diagnosis has caused widespread confusion. According to one psychiatrist quoted by Wallis, AS is not an evidence-based term. At the same time, those concerned that Asperger's Syndrome can still be used by people, who wish to see themselves as they fit into the spectrum, will be reassured that AS has not been totally eliminated from the psychiatric terrain. The new Manual will have the advantages of including, in addition to the core symptoms, also the multiple health issues that usually accompany the disorder such as seizures and gastrointestinal problems.

Temple Grandin is quoted as opposing eliminating AS from the Manual because the diagnosis is too well established, and because there is a large and vocal Asperger's Syndrome community. Others worry that people with mild forms of the autistic spectrum disorder will no longer want to seek medical help. On the other hand, the young activist Ari Ne'eman, founder of the Austistic Self-Advocacy Network, believes that one category of autism will result in better services to our community.

Clearly, Wallis's article will have a mixed impact on the consciousness of the AS population. The impact will also be mixed with regard to the consciousness of mental health professionals. As a matter of fact, it is engendering a lively debate even before the new Manual appears on line. The general public, however, will not be impacted by Wallis's specialized piece.

The increasingly widespread opinions of "experts," as well as the publicity surrounding criminal defenses based on Asperger's Syndrome, have led to the growing belief that we who have Asperger's Syndrome are predisposed to criminal behavior. The literature published by such "experts" will have an extremely negative impact on the consciousness of the Asperger's population, our families, and on mental health as well as legal professionals. These beliefs will be reflected in how our families, friends, educators and employers perceive us. It will also be reflected in the depictions by the media of persons with AS. My intent in the next section is to disprove, or at least cast doubt, on the "findings" of such "experts."

## 2. Asperger's Syndrome and the Law

On November 8, 2008, I looked up on the internet various types of crime ostensibly committed by defendants with AS. The estimated statistics were frightening. Murder: 18,200; Rape: 13,800; Stalking: 16,700; Arson: 1,940; Assault: 11,700; Cyber-crime: 1,230.

These statistics bring to my mind the research I undertook into the epilepsy defense. The article I wrote was published in 1997 in *The Criminal Law Bulletin*. Jack Ruby killed John F. Kennedy's assassin, Lee Harvey Oswald, and unsuccessfully claimed psychomotor epilepsy as a defense. In the wake of the Ruby case, attorneys all over the country began to mount epilepsy defenses. As epilepsy was "hot" in the 1970's, so has Asperger's Syndrome become "hot" since AS became an official psychiatric diagnosis.

In my one-woman play to follow, I initially don the garb of Prosecuting Attorney whose witnesses are journalists, psychiatrists and psychologists. Then I assume the role of Defense Attorney whose witnesses are psychiatrists and psychologists. At the conclusion of this section I become the Judge.

### The Asperger's Syndrome Population on Trial

#### Attorney for the Prosecution

May it please the Court, I am here today as Prosecuting Attorney to bring suit against the Asperger's Syndrome population. These are persons who, due to their disorder, are predisposed to commit serious crimes and therefore pose a danger to law-abiding citizens.

First of all, a significant number of persons convicted of murder have been found to have AS. Statistics found for such cases are alarming: 18,200. The first witness for the prosecution is Donna Schwartz-Watts, who in 2005 published an article entitled "Asperger's Disorder and Murder." This witness found that persons with AS were overrepresented among defendants who committed murders.

Witnesses J. Arturo Silva, with his colleagues Michelle Ferrari and Gregory Leong, found retrospectively that killer/cannibal Jeffrey Dahmer and also "Unabomber" Theodore Kaczynski had AS. The Asperger's defense was not available during the trials of those defendants.

With regard to Dahmer, the witnesses testified in a 2002 article entitled "The Case of Jeffrey Dahmer: Sexual Serial Homicide from a Neuropsychiatric Developmental Perspective." The witnesses found that Dahmers' homicidal behavior was intrinsically associated with autistic spectrum psychopathology, specifically with Asperger's Syndrome. Dahmer was said to evince in childhood poor eye contact, hatred of change, and an aloof manner. In adulthood, Dahmer could not understand the feelings of others. Moreover, he was an avid collector of cadavers, treating his victims as objects.

With reference to "Unabomber" Kaczynski, the witnesses testified in a 2003 article entitled "Asperger's Disorder and the Origins of the Unabomber." Kaczynski's aloofness, inability to understand the feelings of others, aversion to being touched and sensitivity to noise, as well as being old for his age, all pointed to a diagnosis of Asperger's Syndrome. Moreover, he was impaired in social relationships, preoccupied with bombmaking, and evinced an obsessive hatred of technology.

Silva and his colleagues concluded that both Dahmer and Kaczynski represented a subset of serial killers whose lack of empathy was due not to psychopathy, but rather to autistic psychopathology. The retrospective diagnoses offered by these three witnesses have added to the understanding of the evil that may lurk beneath the surface of the Asperger's defendant.

The next witness, Associated Press Writer Ken Maguire, testified in an article published in the January 20, 2007 Boston.com Local News. The article was entitled "Asperger Syndrome in the Spotlight in Murder Cases." Maguire's piece described the AS defense of 16-year-old John Odgren, who in the course of a fight fatally stabbed a fellow student in a school bathroom. Odgren's attorney, Jonathan Shapiro, told the judge at arraignment that his client suffered from Asperger's Syndrome, which rendered him unable to develop social skills. Shapiro described John Odgren as having a hyperactivity dysfunction and as being on medication for many years

Based on the information these witnesses have provided regarding Asperger's murder cases, this Court should see what a great threat such a relatively small population can be to the lives of many innocent victims.

The second violent crime to be considered in the case against the Asperger's Syndrome population is sexual offending. Rape is the most violent of these offenses. Statistics indicate that 13,800 defendants with AS have been tried for rape.

On May 1, 2007, witness Joelle Farrell, Staff Writer for the *Concord Monitor*, testified in a piece entitled "Accused rapist has autism, lawyer says." The Newbury, New Hampshire teenager Robert Derderian, age 18, was accused of sexually assaulting two young girls, ages 10 and 12 respectively. It was alleged that he had sexually assaulted the younger girl seven times during the previous summer. He was accused of also recording his assault on the 12-year-old girl. Derderian had been diagnosed with autism, Asperger's Syndrome, ADHD, as well as with an unspecified learning disorder. Ostensibly the defendant also had limited speech. The expert witness for the defense explained that Asperger's Syndrome prevents children and adults from understanding right from wrong, and also prevents them from understanding reality. Moreover, because Derderian would not speak to his attorney, the defense attorney claimed that the defendant might be incompetent to stand trial.

Your Honor, it is highly probable that the young man's not speaking to his attorney was a ploy to avoid a trial, which would have doubtless resulted in a guilty verdict. In addition, the defendant's alleged inability to distinguish right from wrong and to understand reality would provide a ready-made insanity defense in most jurisdictions.

Although rape does not entail the loss of life, it is a crime that can destroy the psyche of the victim, who often lives with continued shame and rage. A finding of not guilty by reason of a mental defect sends a message to men who rape that if their lawyers can mount a successful Asperger's defense, they can claim incompetence to stand trial. Alternatively, they can be found not guilty by reason of mental defect and the inability to distinguish right from wrong. After a period of hospitalization, such men may be set free to rape again.

Then, Your Honor should consider the high risk of violence women face due to stalkers and molesters with AS. Stalking cases based on an AS defense are recorded as 16,700.

Witness Tom Berney testified in a 2004 article entitled "Asperger Syndrome from Childhood into Adulthood." The witness observed that obsessive harassment or stalking, as well as other offenses resulting from misjudged social relationships, stem from innate AS characteristics. These characteristics include impulsivity, social naivety, misinterpretation of rules, and overriding obsessions. Berney noted that in AS there is often co-morbidity such as dissocial personality disorder and obsessive thoughts, which may be mistaken for psychosis. Here, it is apparent that even a Restraining Order may not deter the obsessed AS stalker from following his prey.

In a 1998 article entitled "Aggression and Sexual Offense in Asperger's Syndrome," witnesses Yoav Kohn and his colleagues described a 16-year-old male who would grab and fondle women in order to make them his "girlfriends."

In a 2002 article entitled "Case History of Comorbid Asperger's Syndrome and Paraphilic Behavior," witnesses John Milton and his colleagues, described a Caucasian male in his early thirties with AS who touched the private parts of young women in public toilets and made obscene telephone calls, pretending to be a gynecologist. These witnesses testified that the subject had co-morbid conditions of AS and a paraphilia. The question here, Your Honor, is whether the paraphilia, which is a sexual disorder, was co-morbid with Asperger's Syndrome or a symptom of AS itself.

Witness Jennifer R. Sentivan, in the May 24, 2007 issue of New Jersey Lawyer, contributed an article entitled "Defendant Should Have Been Allowed to Present Evidence of His Asperger 's Syndrome." Sentivan testified on how in State v. Burr the New Jersey Supreme Court upheld the appellate court's ruling that the trial judge had erred in barring exculpatory defense testimony. The testimony would have provided the explanation that the defendant piano teacher's Asperger's Syndrome caused his socially unacceptable behavior. Under New Jersey Law, this constitutes Diminished Capacity. Defendant Franklin Jack Burr II had been convicted of inappropriately touching a young student while teaching her piano. The prosecution has asserted that the defendant's touching of the student constituted grooming her for sexual assault while he held her in a compromising position. The defendant had been convicted by the trial court of "Sexual Assault and Endangering the Welfare of a Child."

Your Honor, it is abundantly clear that the existence of an Asperger's diagnosis does not preclude the possibility that the person with AS is also a pedophile. Moreover, stalking and molesting may later escalate to rape, or even murder. The Burr case opened a Pandora's Box for pedophiles to get a free pass by alleging Asperger's Syndrome as a defense. Since no actual test for Asperger's exists, it is quite possible for a clever defendant to mount a bogus AS defense. Therefore, this case is especially troubling.

The next violent, and sometimes sexual crime to be discussed is assault, with 11, 700 cases of defendants with AS.

In a 1988 article entitled "An Assessment of Violence in a Young Man with Asperger's Syndrome," witness Simon Baron- Cohen testified regarding the case of a twenty-one-year-old man with AS who was in a romantic relationship with a seventy-

one-year-old woman. Although the young man knew that beating a frail person was wrong, he said that beating his girlfriend made him feel powerful. Baron-Cohen concluded that the young man's assaults were not willful, but rather an irresistible compulsion, like Kleptomania or Pyromania. Whether the assaults were attributable to an irresistible compulsion, or to AS, or to both disorders, this Court can see how depraved a male with AS can be.

Witness Tom Bernay, in his afore-mentioned 2004 article, maintained that undiagnosed AS can lead to inexplicable violence, and that various factors combine to make violent aggression relatively frequent in Asperger's Syndrome. Your Honor will note that Bernay qualifies the danger posed by AS persons, stating that undiagnosed AS can lead to violence. There may be a valid point here, but how can we be sure that people with AS are diagnosed in a timely fashion?

In a 1999 study entitled "A Case of Asperger's Syndrome First Diagnosed in Adulthood," witnesses Bettina Bankier and her colleagues testified regarding a twenty-five-year-old man who had recurrent outbursts of violence and often perpetrated attacks against his mother. The young man also displayed severe social withdrawal and elective mutism. He had also been diagnosed with "obsessional neurosis" and had been institutionalized repeatedly as a child. The witnesses emphasized the importance of early diagnosis of AS in order to prevent such behavior. Your Honor, I agree that early diagnosis might prevent much violence committed by members of the Asperger's community, but that would require many more specialists in the field of AS than are currently available.

In his 2004 article entitled "Early Diagnosis of Asperger's Disorder: Lessons From a Large Clinical Practice," witness Richard Perry testified to menacing and hitting, especially of mothers, as a symptom of Asperger's in the young patients he treated.

This Court surely realizes that a non-fatal assault can result in lifelong injury and trauma. Even Perry, whose article spoke very sparingly of any violence in his patients, acknowledged that menacing and hitting do occur in young persons with AS. The findings of all the witnesses for the prosecution point to the potential of youthful and adult persons with AS to commit assault.

Admittedly, not all crimes committed by persons with AS are intentional and/or violent. For example, in a 1981 paper entitled "Asperger Syndrome: A Clinical Account, "witness Lorna Wing, testified as to one boy who unintentionally injured another boy in the course of an experiment on the properties of chemicals. Nonetheless, this "experiment" could have resulted in the death of the other child rather than just an injury. The absence of a desire to do harm does not lessen the impact of such acts.

Witness Tom Berney, in his previously-cited article, testified that persons undiagnosed with AS tend to commit computer crimes. In fact, Owen Thor Walker, a boy of 18 years old, was the ringleader of an international cyber-crime group and was apprehended by the FBI.

On July 16, 2008 witness Dancho Danchev of ZDNet Zero Day Blog testified regarding this case. Witness Danchey described how at court Walker, who has Asperger's

Syndrome, smiled as the prosecution stated that international investigators considered Walker's programming to be among the most advanced that they had ever encountered. The Judge ordered Walker to pay damages, but no conviction was recorded. In fact, the young man was to be offered a job as a cyber-crime fighter. Your Honor surely realizes that computer crime often entails identity theft, which can destroy a victim's credit and put his or her professional life at risk.

The bizarre obsessive interests of persons with Asperger's may result in crime as well. In the Monday, October 6, 2008 issue of *The Daily News*, witness Staff Writer Pete Donohue testified in an article entitled "Railroad Buff Derailed Again." The witness related how Darius McCollum flashed a bogus badge and a forged ID and was "busted" for the 26th time for impersonating a transit worker. He had also taken a subway train for a joy ride. The man had had repeated run-ins with the law since 1981. In 2004 he was arrested in Queens and put in state prison. McCollum had been diagnosed with Asperger's Syndrome. Admittedly, Your Honor, McCollum was not violent, but his escapades were potentially dangerous to the passengers he took for his joy ride.

In closing this argument, Attorney for the Prosecution urges this Court to realize how dangerous many persons with AS may be to the safety, and even to the very lives, of others.

The Prosecution proposes specialized schools for children diagnosed with AS and group homes to house adults diagnosed with this disorder. In addition, both the children and adults with AS should receive anti-psychotic medications. Although these suggestions may be viewed as draconian, the interests of society at large must be considered. I thank Your Honor for your attention and respectfully request a finding of Guilty.

#### Attorney for the Defense

May it please the Court, I am here as Attorney for the Defense. I speak for countless persons with Asperger's Syndrome who lead lives of quiet dignity and suffer gravely from the publicity surrounding extreme cases of violence committed by persons who allegedly have AS.

I note for the record, Your Honor, that the murder, rape, and assault statistics cited by my esteemed colleague are derived from international cases rather than from United States cases alone.

My first witness is Dr. Richard Perry who provided additional testimony regarding his 2004 article cited by the Attorney for the Prosecution. Dr. Perry acknowledged that some of his patients did hit their mothers. I then asked him whether any of his patients had ever committed crimes. Witness Dr. Perry said that over his 25 years of practice he knew of no patient of his who had ever committed any crime, let alone a violent crime.

Having broadened Dr. Perry's testimony, I will now proceed to the original source of knowledge regarding Asperger's Syndrome: Witness Dr. Hans Asperger

Witness Asperger's thesis for his second doctorate, first published in 1944, is entitled 'Autistic Psychopathy' in Childhood. It was translated and annotated by Dr. Uta Frith. Frith noted that "autistic psychopathy" would be translated as "autistic personality disorder," in order to bring the diagnosis in line with current terminology. Asperger ran a facility at which boys, who had been expelled from public schools due to their unacceptable behavior, were boarded in the "ward" (dormitory) of the facility. The boys were given a unique form of education developed by Asperger. This "Heilpaedagogik" (remedial pedagogy) was tailored to the personalities of Asperger's charges. It was Asperger's belief that the boys' condition was constitutional in origin, or due to an organic defect. One of Asperger's "cases" had brain injury at birth and another grotesquely fat boy had both a brain abnormality and an abnormality in his endocrine system.

The boys taken on at Asperger's facility had similar characteristics. One common trait found among the boys was an inability to accept affection within their families, causing the parents great suffering. Even when not physically alone, the boys were always isolated from others. Asperger believed that this was due to an impoverished emotionality. According to witness Asperger, the boys' general disobedience was not deliberate, but rather due to a genuine defect in their understanding of the other person. Moreover, their perceived rudeness was due to their unawareness of social niceties. They did not distinguish their own mental state from that of others. Although the boys were aggressive at times, Asperger's follow-up of them did not indicate any criminal acts.

Asperger described the boys as victims of abuse and ridicule by their peers, sobbing and flailing while being surrounded by a group of laughing children. Your Honor will note the possibility that these children may have become aggressive solely due to the humiliation they suffered at the hands of his fellow pupils, rather than due to their Asperger's condition.

Despite all the issues his charges manifested, Asperger saw in them redeeming qualities and social value. According to Asperger, these boys were capable of developing and adjusting. Their work performance was usually excellent. With the fulfillment derived from professional success came social integration.

The testimony contributed by Dr. Hans Asperger should convince Your Honor that my client can be socialized and can contribute meaningfully to society. Criminal behavior is not foreordained for persons with Asperger's Syndrome.

The next witness for the Defense is Dr. Uta Frith, who in 1981 made Hans Asperger's work known in the English-speaking world. Frith commented on Asperger's paper in her essay entitled "Asperger and His Syndrome."

Witness Frith confronted head-on the issue of antisocial/illegal conduct in the section of her essay entitled Malice and the Law-abiding Citizen. The witness stated that despite the fact that most people with AS are law-abiding, it must be acknowledged that repugnant behavior does occur. Such offensive conduct will be understood if we

realize that the person with AS does not calculate the effect his or her behavior has on other people. The AS person's lack of theory of mind proves that there is no intent to hurt other people's feelings. Difficult forensic cases involving AS persons arise when the person is pursuing a special interest in a single-minded way, when there is a defensive, panic-induced reaction, or when the AS person is showing a complete lack of common sense. Normally, the person with AS does not deny what he has done and usually feels no guilt regarding the act. Frith concluded this section of her testimony by stating that many people with Asperger's Syndrome are not delinquent but rather excessively concerned with doing the right thing.

Lorna Wing is the witness whose 1981 research on patients with Asperger's Syndrome first kindled interest in this disorder. Moreover, it was Wing who first used the term "autistic spectrum or continuum" to designate persons from extremely low-functioning to extremely high functioning. In "Asperger Syndrome: A Clinical Account," Wing's study of 34 severely disabled patients was described. Among these subjects the witness testified that she found only 4 who had committed antisocial acts. No crimes or acts of violence were described under these antisocial acts.

Your Honor will be aware of the fact that Wing and her colleagues studied very impaired subjects in a clinical setting. The aggressive and destructive children who are referred to clinical settings, therefore, do not reflect an entire population of children with AS.

Witness Digby Tantam authored an article entitled "Asperger Syndrome in Adulthood," in which he testified that persons with AS are described as "strictly law-abiding citizens." Tantam does admit that "in a minority" these features may co-exist with a lack of empathy, which can result in unpredictable violence towards others. However, witness Tantam stated, "unconcern for others is not a universal characteristic of people with Asperger Syndrome."

The major contemporary source of information regarding Asperger's Syndrome is witness Tony Atwood, whose 1998 book entitled Asperger's Syndrome has resulted in Attwood's being acknowledged as the leading expert on the disorder. Attwood did address the issue of criminal conduct. First of all, Attwood testified that only on "extremely rare occasions" do persons with AS commit a criminal offense, usually in connection with their special interests. Attwood was responding to a written query as to whether people with AS tend to commit criminal offenses. Witness Attwood also acknowledged that on occasion violent behavior may occur when sensory issues are involved. He used as an example the violent reaction of an AS person to a barking dog. Moreover, Attwood testified that the strict moral code of a person with AS may result in a confrontation between the AS person and another person who appears to be engaging in "immoral behavior." Attwood, however, assured parents of AS children that their offspring are not likely to engage in criminal conduct.

Your Honor, in 2007 witness Dr. Valerie Gaus published her book *Cognitive Behavioral Therapy for Adult Asperger Syndrome*. This very relevant testimony provides clarification regarding the sometimes-antisocial behavior of persons with AS.

First of all, Gaus testified regarding the difference between Personality Disorders and Asperger's Syndrome, which is a Developmental Disorder. The witness explained that although AS can appear to be a Personality Disorder such as Antisocial Personality Disorder, the individual with the personality disorder intends to harm others. On the other hand, the person with a developmental disorder such as AS does not have such an intent. Your Honor will note that Gaus does not preclude a person with Asperger's Syndrome also having a personality disorder.

Witness Gaus acknowledged that addiction to drugs or alcohol may be a cooccurring disorder in persons with AS, who seek to alleviate their anxiety. Clearly, if an AS person is found with illegal substances, he or she will have a criminal record.

Gaus also warned that sexually offensive behavior, which may be illegal in the community, does occur in some cases of AS. Gaus, however, differentiated between "counterfeit deviance" (as exhibited in AS) and cases, which require specialized treatment for sex offenders by an expert on forensic issues.

Moreover, Gaus testified that the odd behavior and poor social judgment of persons with AS may also lead to legal problems. Gaus cited as an example a young man who was pulled over by a police officer. Based on the averted gaze of the man, the officer concluded that the individual was guilty of some violation. When the young man yelled and threatened the officer, he was taken to the precinct. Although he was subsequently released, that young man was afraid of the police for many years.

Witness Gaus explained that bizarre reactions to stress and poor social judgment may lead people in the community to provoke persons with AS, and then to report them as a threat. Lack of understanding of social norms may lead people with AS to break the law outright. Nowhere in her book did Gaus even imply that the average person with AS is inherently predisposed to criminal behavior. In addition, I remind the Court that Gaus's experience with AS cases is based on her contact with depressed or anxious persons referred to her by family members or employers, rather than on contact with persons not requiring therapy.

In their essay entitled "Diagnostic Issues in Asperger Syndrome," witnesses Volkmar and Klin testified that with regard to violence, the person with AS is far more likely to be a victim than a victimizer, and that the available data do not support the alleged connection between AS and violent criminal behavior. Overly rigid and moralistic, persons with AS are deemed by these witnesses to be "perfect victims."

In an essay entitled "Adolescence and Adulthood in Individuals with Asperger Syndrome," witness Digby Tantam testified that in his experience, people with AS rarely commit theft or sexual offenses. In fact, they tend to be victims rather than perpetrators. The witness listed typically co-occurring conditions with AS: Depression, anxiety, OCD and Tourette's Syndrome. This Court will note that witness Tantam did not list any personality disorder such as Anti-Social Personality Disorder as typically co-occurring with AS.

The final witnesses for the defense are Stewart Newman and Mohammad Ghaziuddin, who testified in an article entitled "Violent Crime in Asperger Syndrome: The Role of Psychiatric Comorbidity." Their testimony raises an issue often touched upon in other witnesses' testimony: That people with AS often have superimposed or comorbid psychiatric conditions. The witnesses had a limited number of subjects(only 37) whose records they were able to study. They testified that at the time of committing the violent crime, 11 (29.7%) of these subjects had a definite psychiatric disorder, and 20 (54%) had a probable psychiatric disorder. The witnesses concluded that their findings underscore the role of psychiatric disorders in the occurrence of violent crime in persons with Asperger's Syndrome and highlight the need for early diagnosis and treatment. The term "psychiatric disorder" in this article included personality disorders(such as Antisocial Personality Disorder) and Impulse Control Disorders (such as Pyromania or fire-setting). There were four cases of depression and three schizoaffective cases.

Your Honor, is it not possible that the violent crimes committed by the persons with co-morbid psychiatric conditions were committed solely due to the co-morbid psychiatric disorder, and not due to Asperger's Syndrome?

Having discussed the research findings of the various witnesses who are all highly regarded in their respective fields, I now respectfully remind this Court of the old saying, "silence speaks louder than words." By this I mean that if Asperger's Syndrome were associated with any psychiatric or personality disorders characterized by antisocial and criminal conduct, this association would be expressly included in the symptoms or co-morbid conditions. I will cite various sources utilized neither by the Prosecution nor the Defense.

Let us begin with the major source, the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revision of 2000, known as the *DSM-IV TR*. First I will enumerate specific disorders frequently associated with antisocial and/or criminal conduct. For the record, your Honor, under "Asperger's Disorder," antisocial and/or criminal conduct is not listed under "Associated Features and Disorders." Perhaps this omission can be attributed to persons with AS being, for the most part, neither violent nor criminal in their conduct.

Among the disorders usually diagnosed in infancy, childhood or adolescence, antisocial conduct is listed under Oppositional Defiant Disorder and under Conduct Disorder (the precursor for adult Antisocial Personality Disorder). However, with regard to the these two disorders, Asperger's Disorder does not appear under "Associated Features and Disorders."

With reference to mental disorders diagnosed in adulthood, Schizophrenia, Manic Episode in Bipolar Disorder, and Anti-Social Personality Disorder may encompass violent antisocial and/or criminal conduct. In fact, a diagnosis of Antisocial Personality Disorder requires criminal behavior to have occurred. Again, Your Honor, Asperger's Disorder does not appear under "Associated Features and Disorders."

Although some individuals with Asperger's Syndrome also become substanceabusers or alcoholics, Asperger's Syndrome is not mentioned in reference to Substance Abuse in the *DSM-IV*. Thus, it is fair to say that if any violent criminal act occurs when a person with AS is under the influence of alcohol or a drug, such an act is attributable solely to the effect of the alcohol or drug, and not to the combination of the alcohol/substance and Asperger's Syndrome.

The *DSM-IV* is an extremely comprehensive authority on all forms of mental disorders and would surely have listed Asperger's Syndrome, or Disorder, if it were even remotely associated with all the above-cited psychiatric disorders.

The next source to be referenced is Carl B. Gacono's text, entitled *The Clinical and Forensic Assessment of Psychopathy*, published in 2000 (post *DSM-IV-TR* Asperger's Syndrome diagnosis). Not one of the authors who contributed to the text referred to Asperger's Syndrome with regard to any aspect of psychopathic behavior.

Finally, there is Louis B. Schlesinger's text, entitled *Sexual Murder*, published in 2004 (again post *DSM-IV-TR* Asperger's Syndrome diagnosis). The book contains not one single reference to Asperger's Syndrome. It should be noted that Schlesinger discusses a very broad spectrum of homicides and is known internationally for his work in profiling the homicidal offender. Although Jeffrey Dahmer is discussed in Schlesinger's text, there is no intimation of Dahmer's having any autistic spectrum disorder.

I am most grateful to this Court for providing me with a forum to dispute the Prosecution's claims that the Asperger's Syndrome community is inherently violent and prone to criminal conduct. I do not dispute that persons with AS, both in child-hood and adulthood, may have tantrums and become aggressive. However, aggressive behavior is not tantamount to violent crime.

I do agree with the Prosecution that measures should be taken when violent acts occur, often due to panic or to bizarre preoccupations rather than to anintent to harm. However, segregating such AS children by putting them in special schools is not the answer. Equally inappropriate is the proposal to place adults with AS in group homes, as well as to medicate them with anti-psychotic drugs

I would suggest early intervention in the form of specialized AS counseling for the children. For the adults, I suggest intervention in the form of specialized AS counseling, with anger management as a major component. For persons with AS who commit crimes other than murder, rape, or serious assault, I believe that referral to a Mental Health Court would be the ideal solution. Such a court would mandate specialized counseling as a condition of probation. Carol Fisler, in her article "Building Trust and Managing Risk: A Look at a Felony Mental Health Court," describes what such a court can achieve.

I speak in the name of the countless persons with AS who, while harming no one, suffer discrimination, loneliness and lack of fulfillment due their condition. I therefore respectfully ask this Court for a ruling of Not Guilty.

#### Judge

Today this Court has been asked to decide a case without precedent. Can an entire disability population be found guilty of criminal conduct when, in the overwhelming majority of cases, that conduct is only predicted and has not yet occurred?

The United States has a sordid history with the internment of Japanese-American citizens during World War II, based on the assumption that their national origin made them a threat. The mentally disabled were hidden in attics and cellars, or warehoused in back wards of institutions, because they were feared as "possessed" or "crazy" and, therefore potentially dangerous. These unjust social conditions, for the most part, no longer exist. Nonetheless, the Prosecution's views are an indication that the mindset that gave rise to such conditions still flourishes, even in the legal setting. I hope that the Prosecuting Attorney never experiences having a child diagnosed with Asperger's Syndrome or with any other disability, which has a negative impact on behavior. Segregating AS children and adults amounts to incapacitation, which means taking punitive legal action before the wrongful conduct has occurred. This violates the Due Process Clause, as well as both the letter and the spirit of the U.S. Constitution.

In only one respect do I agree with the Prosecuting Attorney: Asperger's Syndrome has become a "hot" defense for attorneys, who will use any means to secure a verdict of Not Guilty, or at least a lighter sentence. Unlike epilepsy, used in the 1970s and 80s as an often- bogus defense, there is no accepted medical test such as an EEG for Asperger's Syndrome. The symptoms may be mimicked by a defendant with knowledge of AS and good acting talent. The sensationalism surrounding this disorder is harmful to the Asperger's Syndrome population and, clearly, to the legal community as well.

The attorney for the Defense correctly acknowledges that measures need to be taken when children with AS exhibit aggressive behavior, and when adults with this condition have encounters with the law due to their sometimes disturbing and even unlawful behavior. Mitigating damages is a legal principle, which applies both to plaintiffs and defendants. This means that the party has a duty to take action, which will reduce or minimize any damages. Here, parents of AS children have an obligation to ensure that their children are provided with appropriate counseling in their schools. A few hours a week in the school psychologist's office can suffice to effect change in behavior. Adults with AS, who encounter legal problems relating to their employment or due to an alleged criminal act, need to reach out to the appropriate Human Resource counselor, or to retain counsel. The Defense Attorney correctly suggests referral to a Mental Health Court.

I fervently hope never to see such a case come before this Court. Not Guilty.

#### End of Trial

Although my format for the issue of crime in the Asperger's population is decidedly unconventional, I hope that the prejudice against those of us with AS will dramatically impact the reader of this section. It has been a lacerating experience for me to deal with the frightening material regarding our condition. Most distressing to me is the knowledge that the consciousness of many members of the public, who hear or read of violent crimes committed by persons with actual or alleged Asperger's Syndrome, will be negatively impacted. Such a negative impact will result in the bias against us increasing dramatically. Even those of us who suspect we have AS may be too frightened to seek therapy or a support group. This is what initially happened to me.

Before proceeding to a discussion of Asperger's and employment issues, I will present a criminal case in which a brilliant young man was unjustly convicted of an act of ecoterrorism and thus unable to fulfill his outstanding potential for a brilliant career.

#### Judith Lewis, "A Terrible Thing to Waste"

In the February 28, 2007 issue of the *L.A. Weekly* Judith Lewis described the tragic fate of Billy Cottrell. Cottrell had been a brilliant student of theoretical physics at the California Institute of Technology in Pasadena. Expelled from high school, he wrote an essay that qualified him to study at Cal Tech, where he was viewed as an eccentric although amiable doctoral student. He was never suspected of being dangerous, only "a few degrees removed from reality."

Other scientists considered him a genius. He had not yet been diagnosed with Asperger's Syndrome. Ironically, Cottrell was anything but radical. Nor was he involved with the environmentalists. He had voted for Schwarzenegger and routinely read *The Nation*. He believed that most problems were due to people's laziness.

One evening some friends of Cottrell's induced him to participate, for the sake of the environment, in what seemed a harmless prank of spray-painting gas-guzzling hummers in various lots in Los Angeles. However, Cottrell's friends actually blew up the hummers. Cottrell, socially naïve due to Asperger's Syndrome, was arrested along with the young men who had planned the explosion. At trial, Cottrell's attorney was not permitted to explain that his client's Asperger's Syndrome had made him naïve enough to believe that the other young men were only going to spray paint the cars. Among the graffiti on the cars was "ELF" (Earth Liberation Front), which never really existed as an eco-terrorist group, but only as website and front for the sale of Viagra. The judge did not accept the defense proffered that Cottrell's condition merited leniency. Instead, the judge added time to his prison sentence, ruling that Cottrell was to serve 8 years instead of the routinely-imposed 5 years.

In prison Cottrell was tormented by the other prisoners who believed him to be a terrorist and found him "freakish." The guards disliked him because he would not play their games and refused to assume a subordinate attitude. Moreover, because he was viewed as a dangerous terrorist, Cottrell was denied the right to be the secretary of the prison, or even to mow lawns. Instead he was given the job of sorting through the dumpsters with the detritus of his fellow prisoners. He was not even permitted to study the Chinese language.

Eight prominent scientists wrote a letter protesting the treatment accorded to Cottrell. One of these scientists observed that "if Billy's treatment does not change, then by the time he will have served his full sentence, Billy will have ended up a human wreck unsuited for any constructive participation in American society."

This article functions on two fronts: First, the reader can see how a person with Asperger's Syndrome can be deceived into participating in criminal activity without having the requisite intent to commit a crime. Secondly, the reader can see how ongoing discrimination and abuse can destroy the potential of a brilliant and gifted person with Asperger's, and how this abuse can also rob the employment world of possibly great contributions.

### Asperger's Syndrome and Employment Law

Just before I began working on the relevant section of this book, I googled "Asperger's Syndrome and Employment Discrimination." As of January 5, 2009, there were approximately 11,700 entries. This section of the book will be approached as follows:

A discussion of Susan Stefan's book *Hollow Promises* will provide the legal background to the section. The text deals with the failure of the Americans With Disabilities Act (ADA) to protect people with mental disabilities,

A discussion of several articles on Asperger's Syndrome and employment will furnish a picture of AS and its impact on employment. This will be accomplished through the inclusion of brief personal accounts by adult AS employees, and by citing therapists' perspectives. Essays written about the employment experiences of GRASP meeting participants will enhance the perspectives provided by the articles.

The Conclusion will emphasize the success stories of employees with Asperger's Syndrome, but it will also warn of the many obstacles still preventing people with AS from fulfilling their potential in the employment world.

#### Susan Stefan, Hollow Promises

Susan Stefan is an internationally-respected attorney and writer on the issue of mental disability and the law. I will discuss the chapters of her book, which are applicable to persons with Asperger's Syndrome. Although Stefan never mentioned Asperger's Syndrome in her text, many sections apply to our population.

Among the many discrimination cases listed by Stefan there was only one 2000 case involving an autistic employee who might also have been diagnosed with AS. Moreover, Stefan listed autism under the rubric of Severe and Persistent Mental Illness. The author included schizophrenia and bipolar disorder as psychiatric disabilities per se. According to Stefan, psychiatric disorders listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) are "mental impairments" for the purposes of the ADA; however, few disorders in the DSM-IV are presented as disabilities in ADA litigation. Stefan emphasized that discrimination and stigma are more harmful to the mentally disabled person's work performance than the disability itself. In mental disability cases, there is rarely discrimination in hiring due to the prohibition of

the ADA against asking whether the person has a disability. Normally, the mentally disabled person encounters interpersonal problems once on the job. Although Stefan cited employees with depression as an example of such a situation, people with AS would likely encounter interpersonal problems as well.

The situation where an employee manifests a psychiatric condition due to stress and interpersonal difficulties, and may even be hospitalized and put on medication, is often classified as not a disability by the court. Rather, Stefan explained, the courts recognize only the biological model of mental illness and ignore the fact that psychiatric disabilities are contextual and affected by interactions. Moreover, courts classify episodic attacks of a psychiatric disability (e.g. a manic episodes occurring once a year) as temporary disability, like a broken leg, i.e. not protected under the ADA.

Many courts might consider AS to be a personality disorder rather than a major psychiatric disorder, such as schizophrenia and depression. Stefan spoke of the Disability versus Personality dichotomy (i.e. mental and psychological disorders versus common personality traits, such as poor judgment and quick temper where they are not *per se* symptoms of a mental disorder). Among these common traits Stefan listed are the inability to tolerate stress, interpersonal/social difficulties, and periodic difficulties in concentration. All these traits are common to AS.

Another issue of great concern to the AS population is misconduct on the job. Stefan noted that disability-based conduct should not be punished if similar conduct not arising from disability is punished differently, or not at all. Drinking alcohol or assaulting someone while on the job would be examples of conduct punishable whether the person is disabled or not.

Stefan distinguished between discomfort due to the appearance (e.g. tremors) of an employee with a disability, and discomfort due to the behavior (e.g. screaming obscenities) of a disabled person. Mental retardation is the only disability, where discomfort with behavior is not grounds for adverse employment action, such as suspension or discharge.

The author described the case of a man who had brain damage due to an accident. He was unable to respond to social cues, and he exhibited bizarre behavior such as refusing to let a fellow employee pass through the door unless she gave him a lick of her ice cream cone, asking embarrassing questions about a training bra, clucking in the face of an employee who was carrying an umbrella with a duck's head, and falling to his knees begging a female employee not to cut her beautiful long hair. The plaintiff in this case did not prevail. I am sure that some of us in the AS Community can identify with the concept of bizarre behavior and its consequences. It is only fair that extremely distressing behaviors not be tolerated. Although many of us with AS are eccentric, annoying, and inappropriate, I believe that our behaviors generally do not rise to the level of disrupting others at their work or causing fellow employees to fear for their safety.

Stefan's chapter on abusive work environment is highly relevant to people with AS. She listed four categories of complaints filed by people with psychiatric disabilities: 1. An employee with past success on the job has interpersonal problems with a new supervisor. This is the most typical complaint, but courts tend to reject the idea that disability can be triggered by dealing with other people. 2. The employee has a psychiatric disability arising from other work environment issues such as sexual harassment. 3. The psychiatric disability is due to additional workplace demands(e.g. longer hours and more responsibilities), where a reasonable accommodation was requested but denied. 4. Employee misconduct such as sexual harassment resulted in discipline, and the employee alleges that the discipline showed that the supervisor perceives him/her as disabled (e.g. calling the employee "delusional"). Here it should be noted that the ADA protects non-disabled employees who are "perceived as" disabled. Such misconduct may include assault and criminal acts. Despite the widespread public focus, this category of complaint is in the minority.

Stefan maintained that many psychiatric disabilities were not pre-existing, but rather were triggered by work conditions that could easily have been ameliorated by means of reasonable accommodation. Such employees are often long-term, dedicated, and competent individuals. Mentally disabled employees rarely exhibit the behavior believed to be common to the mentally ill, whereas the employer frequently evinces stereotypical discriminatory attitudes. Courts generally decide against employees who cannot cope with stress and abuse from employers and co-workers. This is because courts do not view this limitation as a diagnosable disability, such as schizophrenia. Rather, courts view it as stress, which is not a diagnosable mental disability.

Handling stress, as well as getting along with others, may be deemed essential functions of a job, and the employee who cannot meet these standards will be deemed not a qualified person with a disability. In cases involving physical disability an employee may be transferred if the stress is exacerbating his/her condition.

On my job with the New York City Correction Department, one of my reasonable accommodation applicants had epilepsy, and her seizures increased due to a hostile supervisor. She had been on light duty in an infirmary and was kept there until her retirement rather than being sent back to the facility, where she would have had to work under the abusive supervisor. However, another employee whose depression increased due to an abusive supervisor was refused the same accommodation. This refusal occurred despite my efforts on her behalf. Both supervisors in these cases screamed at the employees and thus caused exacerbation of their conditions, but the distress experienced by the employee with a mental disability was trivialized.

Stefan noted that the law has come so far as to prohibit racial epithets and sexual harassment, but it has not progressed to the point where a supervisor is prohibited from screaming at a mentally ill employee. The ADA requires that the disabled employee be "substantially limited in a major life activity." However, the ADA does not cover being unable to work with a particular supervisor. If the person can work with another supervisor, he/she is deemed not to be disabled within the meaning of the ADA. Stefan reminded the reader that the fragility that makes the supervisor's abuse untenable does go with the disabled person to the next job. It is only in mental disability cases

that courts look to the cause of the disability (brain abnormality versus interpersonal conflict). The author acknowledged that some jobs are inherently stressful, such as a police officer's need to be able to handle stress when dealing with crime. However, a supervisor's yelling at an employee may not violate the ADA, unless the supervisor's yelling at the mentally disabled employee includes discriminatory language such as "nut case" or "crazy."

A major issue in ADA litigation is "disparate impact." This means that an employment action applied to all classes of employees impacts more negatively on one class of employees. In race cases, an example of disparate impact would be aptitude tests, required by all prospective employees, which have impacted more severely on minorities. If a supervisor calls all his/her employees nasty names, severely affecting only a mentally disabled employee, disparate impact will rarely be invoked as a cause of action. Stefan qualified that although disparate treatment is the most commonly-invoked cause of action, disparate impact is prohibited by the ADA as well. Stefan maintained that employees with mental disabilities react more severely to the equal opportunity abuse of supervisors who abuse African Americans, women, and disabled persons indiscriminately. Moreover, disparate impact never occurs as exclusion in the hiring process, but only when extremes of abuse and stress occur on the job.

Stefan concluded that hostile work environment claims are rarely successful because "hostile" is too vague a term. She also suggested that a polite work place culture would benefit all employees, not just those with mental disabilities

Susan Stefan devoted an entire chapter to clarifying the issue of reasonable accommodation. This issue is especially relevant for those of us on the autistic spectrum.

First of all, Stefan stated that employees rarely win on reasonable accommodation claims in court. Among the reasonable accommodations most frequently requested, Stefan listed thirteen. Eight apply to persons with AS (instructions in writing, room dividers, flexible hours, change of supervisor or transfer, less stress, and reduced noise and/or lighting). For persons with physical disabilities, it is a question of ramps or interpreters. For persons with mental disabilities a transformation in attitude is required.

Under the ADA a qualified employee is one who can fulfill the essential functions of the job, with or without accommodation. Stefan explained that the problem often arises when the employer adds non-essential functions to the workload. The aim of this is to maximize profits and minimize the number of workers. If a disabled employee is unable to perform a non-essential function added to the job, he or she is still protected under the ADA.

Some tasks which a person with a mental disability cannot perform may, or may not, be deemed essential functions. For example, working at home may be viable in a large company, but not in a small firm. Working long hours has been held to be an essential function in certain professions such as the law. An attorney with a mental illness, who could not handle long hours, was held, for the purposes of working in a law firm, not to be a qualified individual with a disability. The inability to work irregular

shifts was an accommodation not considered reasonable for a Correction Officer in a jail, whereas it was considered reasonable for the Warden's secretary. Social skills may be considered an essential function in a job with heavy customer contact. Here, a person with AS who is insubordinate with co-workers, supervisors, and customers may be deemed unqualified, since social skills are needed to promote harmony in the organization. For a person with AS working in a secluded space doing data entry on a computer, it is obvious that social skills would not be an essential function.

Many people with mental disabilities self-accommodate, and the employer may remain unaware of a disability until the stress escalates to a level where the employee must disclose and request an accommodation. When the employee holds off disclosing until major problems occur, the disclosure may be viewed with suspicion.

Stefan noted that an employer may request a physician's diagnosis in writing before granting an accommodation. In my position at the Department of Correction, I had to routinely request that the applicant for the accommodation provide such documentation. Whereas employees with physical disabilities were usually granted accommodations, those with mental disabilities were usually denied the accommodation despite excellent and detailed documentation by highly- qualified psychiatrists or psychologists.

Many employees claim that they suffer discrimination on the job. Stefan devoted a chapter to this term, as it applies to the ADA. Adverse employment action is required for a discrimination claim. Salary or terms and conditions of employment must be changed in a way that it is detrimental to the employee and the change must be based on the employee's disability. An example of such action includes discharge. Of special concern to persons with AS is psych testing (Profiling), which screens for behavior problems. This type of screening is not under the purview of the ADA because it does not screen for *DSM-IV* mental disorders, but rather for "emotional instability." "Personality tests" are administered by non-psychologists but created by psychologists. If an employee with AS refused to take such a test, he or she would be found to have been insubordinate. Insubordination is a non-discriminatory reason for termination. However, such a personality test must be required for all employees of the particular employer.

Under the chapter on discrimination Stefan included a section on misconduct, which is very broad. For example, a professor who is found to have sexually harassed a student may use the defense of a mental disability. Stefan noted that paraphilias (sexual disorders), as well as impulse control disorders, such as pyromania, and illegal drug use, are not protected under the ADA. Only the drug user who is not using, but in recovery, is protected by the statute. Pertinent to those with AS is the fact that many disabilities manifest themselves in a particular form of behavior. This includes the barking common in Tourette's Syndrome, or the flailing of limbs in epilepsy. These behaviors are protected under the ADA. Only if there is a risk to the health and/or safety of others, may the employer use the "direct threat" defense in a mental disability discrimination case. If a man with AS is found to have sexually harassed a female

employee because he cannot read her social signals, the best remedy would be to transfer him from her area. If he stalks her, discharge would be appropriate.

Stefan noted that co-worker discomfort is not grounds for adverse employment action in cases where a mentally disabled person speaks loudly, has crying spells, or makes strange noises. The author also enumerated the types of ADA discrimination cases, which are often successful: Retaliation cases don't require proof of disability; complaints litigated under state law often provide broader protection than the ADA; intentional, overt discrimination cases succeed, where the employee has a history of success with the employer. However, a situation that arises early in employment may be suspected to be bogus. Finally, Stefan emphasized that an employee has a good chance of prevailing if the employer is a mental health provider, rather than a police department or a bus company, where public safety is implicated.

Stefan's book provides the background for understanding the plight of people with Asperger's confronted by the legal realities of the work world. However, the sophisticated text will not impact on the consciousness of the general public.

The next section dealing with the work world entails a discussion of various articles on Asperger's adults dealing with employment issues. Although adults with AS usually don't encounter obstacles until they are on the job, some highly- gifted persons with AS are unable to undertake the education necessary to begin a career appropriate to their interests. People who have AS are often either unemployed or underemployed. I was gratified to see that some of the articles described success stories, but such successes are not always in the fields in which the AS persons originally hoped to work.

#### Articles on Asperger's Syndrome and Employment

Jaimie Talan, Staff Writer, "A World Apart from Autism," published in the January 20, 2004 issue of *Newsday.com* 

An example of a highly talented young man with AS, who was not employed in a position commensurate with his abilities, was described in this piece. Eric Schissel, who went to graduate school at Cornell University, was unable to work in a team situation and therefore did not complete the graduate program. Eric was diagnosed with Asperger's Syndrome in the 1990's. The employment Eric subsequently found was cataloging plants for the Horticulture Department at Cornell University. The author of this article wrote that in one study fewer than 1% of the Asperger's patients questioned said that they were doing what they were trained to do. The brief accounts included in Talan's essay would likely evoke compassion in the reader and thus have a positive impact on the public consciousness.

Although many people with AS do work in the Information Technology(IT) industry, the picture is not as rosy as it may appear.

Tracy Mayor, "Asperger's: The IT Industry's Dark Secret," published in the June 23, 2008 issue of *Computer World, Framingham, New Zealand*,

In this piece the author described the professional lives of three men with AS who had worked in the IT industry. Ryno, who was 50-something, was a former Systems Administrator living on disability in rural Australia. He had loved the technical aspects of his job, but he found the interpersonal interactions required by his position to be unbearable. Ryno initially fared well in his job and even had a boss with AS, but the systems they created together to minimize interruptions were resented and not used. Finally, Ryno quit when he was ordered to restore the internet access for an employee who had downloaded pornography against company policy. Ryno claimed that tech is to Aspies what water is to fish.

The next AS male in the IT industry described by Mayor was Jeremy who was a well-known engineer and the go-to guy in the industry. His frankness upset his co-workers, and he had no tolerance for office politics. When Jeremy requested an accommodation, he was fired. Although he had never received negative feedback on his work performance, he was forced out of the job.

Mayor finally described Bob, a database applications programmer in high tech. He had been working in his field for 26 years. Although Bob's boss was frustrated with Bob's literalness, the boss understood that the behavior was not willful. The author noted that that he would be considered a "stereotype," since a higher number of people with AS are employed in high tech than in other professions. Bob had praise for Google, where employees were encouraged to bring dogs to work and prepared meals were supplied for the workers.

Mayor's article revealed the IT industry's "dark little secret:" That, with the exception of coverage for therapy included in the health care plans, there is not one single corporation with a formal program in place for employees with AS or HFA. The author's piece should have had a strong impact on the public consciousness, with readers probably being surprised and even angry upon learning of the obstacles confronting AS"techies."

Some adults with AS have found great professional gratification in areas not related to information technology. The next article to be discussed will illustrate the potential of persons on the autism spectrum to successfully interact with others and, moreover, to use their Asperger's Syndrome to help person with AS.

Meg McSherry Breslin, "Free To Be Themselves," published in the June 27, 2007 issue of the *Chicago Tribune* 

The author first introduced Brian King, a clinical social worker, who is proof that people with AS are able to work in fields where interaction with people is a major function.

A rather unconventional "success story" presented by Breslin concerned Thomas Mazanec who was diagnosed with AS just before he was fifty years old. At school, Thomas was ridiculed by his peers and called "retard." He was awarded a Bachelor's degree in astronomy, but he lost any job he managed to obtain. Then he went back to school and was awarded a Bachelor's degree in Computer and Information Science. After that, he lost job after job. Thomas consulted many psychiatrists and received many

diagnoses. He was unemployed for many years. Desperate for employment, Thomas took a job as a janitor at Brendan Manor, a rooming house for gifted but mentally challenged adults. His boss, Executive Director Diane Kalchert, became his best friend and was very pleased with his work at the house. She suggested that he go to a psychiatrist, where Thomas was finally diagnosed with AS.

Kalchert saw Thomas transformed by the diagnosis. He felt worthwhile for the first time and shared with the larger community his experiences of life with AS. Kalchert called Thomas "brilliant and a perfect example of hope." Breslin's article has the potential to impact very positively on the public consciousness because stereotypes are challenged, and increased hope for employees with AS emerges.

When I told my GRASP support group of my book and solicited personal accounts regarding employment, I received many responses and selected for inclusion accounts, which differed from each other and with which the reader would identify. To protect the privacy of the contributors I have used only first names.

#### Essays by Members of the GRASP Support Group

The first submission was from Tom, who possesses a quiet and radiant charm. He was there for me when my beloved cat died. Tom knows how to comfort others. Rather than being socially inappropriate, Tom experiences problems with following instructions given for the first time, focusing, physical coordination, and required speed. Tom's essay is especially valuable because he diverges from the stereotypes of AS (geek, loner or socially inappropriate). It is also relevant because Tom has ADHD and OCD, with which persons with AS are frequently diagnosed. This essay also points up the need for aptitude testing and career counseling at college. A professional counselor would probably have steered Tom away from any kind of mechanical work and towards work with people.

#### "Work Life of an Aspie" by Tom

#### CRR-RR-UNCH!!

The van swiped the wall in a curve in the tunnel, with me alone at the wheel. I backed up, hit the brake, and gazed through the back window to behold my boss. He stood, sullen, hands on his hips, focusing on me from across the floor. Loudly and steadily, he said: "Youuuu blew it!"

Car-washing and car-jockeying had been my lot after ruining a paint job while carbuffing for the same company. Staying on with the company had been a fight. My new boss had just told me that the work on the van was done, and that I needed only to rinse the vehicle off upstairs after taking it up the tunnel. Fired I was. Again! From the third company, at age 22, in four months! The fact that I suffered from an internal "wiring" problem was horribly clear. I learned that I had Asperger's Syndrome (AS). My history is filled with AS traits such as a lack of motor coordination, poor manual speed, an inability to keep up with others, poor social skills, failure to concentrate, failure to "get it" the first time I hear instructions, bad short-term memory, poor perception of cause-and-effect, and failure to "read" people. They are hindrances that continually doused me with disappointment and confusion, which challenged my self-worth. Despite my eager commitment always to do right and succeed, frustration and ever-worsening performance resulted.

My work experience involved failure to ever "hold down" a full-time job for over two years at a time. I'm now 55 years of age. Came evaluation time at the shoe store where I have been employed, my supervisor spewed out at me that I was too slow and that she had wondered, "what is he thinking?" when I would be cleaning up on one aisle instead of skipping to the next aisle which was messier. She noted that I had a puzzling need to be "methodical," a term another boss, decades earlier, had used for my approach to tasks. Does this sound familiar? AS! Right! Indeed,

AS was the whole trouble. Stupidity? No! I had graduated from two colleges and a test revealed that I had an above-average IQ. Laziness? No. Bosses always praised my hard work and punctuality. Dishonest? No. My rigid principles disturbed even foremen on jobs, and they said so! Abrasive and unfriendly? No. Supervisors repeatedly praised my courteous conduct.

I was sick of hearing, "this job is not your forte" at so many different kinds of jobs. Therefore, it was such a relief to discover I was neither guilty nor goofy! My depression finally ended. AS was "nailed" as the cause of the problems. Now it could be addressed. I owe a debt of gratitude to the research on AS in the fields of psychology and psychiatry, and also to a local group of "Aspies" I have joined. As a result, I am doing better on my job, enjoying it even more, and it's been 2 years! So far, so good.

I'm selling shoes on commission and receive a salary. Only after I was hired did I tell my supervisor something of my problem, and that was so that he would work with me on it and also know that I am neither lazy nor disinterested. He is a good boss, and it has worked out! Dealing with people is becoming much easier, too. Knowledge is truly power, which proves that this incurably slow tortoise can find the strength to be steady enough to win the race.

The author of this book, whom I know as "Irmi," asked me to reveal the major reason for my patient endurance of all the difficulties in my work life – indeed in all aspects of my life. By the time I had reached the age of eighteen, I was suicidal. All I knew was failure and ostracism. It was then, in 1972, that I decided to entrust my life to my Lord Jesus Christ. One of the greatest things He did for me was to immediately grant me a forgiving heart and an acceptance and appreciation of my own personhood. He touched me at the deepest, most fundamental level of my need.

As for me, since 1972 I have not looked back, and I will never will look back again. Although my life has not been "a bed of roses" any more than any one else's has been, Jesus Christ, whom I believe to be the Son of God, gives my life meaning even through

all the pain. Finding a new birth through Him is real and powerful, and Jesus has made all the difference in my life.

Tom's story is one of hope. He has not "made it," in the conventional sense. However, he is at peace with himself and with the world. It is clear that for him his religious belief has been a major factor that moderates his Asperger's Syndrome symptoms, such as anxiety and depression. This story, if widely read, would have a very positive impact on the public consciousness.

The opportunity to meet Tom in person would have an even more positive impact. Even the readers, who do not share Tom's belief in Christ, would realize that different life-circumstances work for different people with AS. Tom has found a church where he finds opportunities to be of service. He is very happy now.

The next account is written by a woman of about sixty years old, who makes independent films. Her story is structured in a highly organized manner. This is typical of some of us on the spectrum who have a spot for every item in their homes, and who are valued at the work place for their ability to get assignments due tomorrow submitted by yesterday. Like Tom, Daina has found a way to be at peace with her life. Daina's narrative began with detailed descriptions of babysitting jobs and work at school cafeterias. These experiences revealed Daina's Asperger Syndrome characteristics and caused her problems with employers as well as with the children she babysat. Her story is taken up when she arrives in New York to study filmmaking.

# "All About Employment" by Daina

Employment has been such a confusing, and often contradictory, issue in my life that a sensible presentation requires a high degree of organization. For each job I will try to cover:

- 1. How the job was obtained and the nature of the job in terms of actual "work."
- 2. The nature of the social expectations and how I did, or did not, deal with them.
- 3. Why I succeeded at the respective job, or why I did not succeed.

Once I decided to move to New York and study filmmaking in order to make myself as independent as possible, it also became apparent that I had to figure out a quick way to make some money. I practiced typing for several hours a day and brought my typing speed up. This enabled me to obtain summer work through various New York City agencies. Soon I came to understand many of the ramifications of being whatever I was, which was profoundly different from what was socially acceptable. I also knew that this was not going to change, and that in order to make enough money to survive I would have to sidestep the social expectations in some way.

Temporary Typist in Offices in New York City and Los Angeles

When a temporary employee is hired, it is usually because there is work that needs to be done. Since the temporary typist will be there for only a short time, the social expectations are momentarily set aside. Because of my typing speed and knowledge of English spelling and grammar, I was able to obtain jobs very easily. These jobs were often interesting. The most memorable was my assignment at the Frick Collection in New York where I worked for almost an entire summer.

I worked at many temporary jobs as a typist/word processor throughout my studying for my Bachelor of Fine Arts at New York University as well as for my Master of Fine Arts in film from Cal-Arts –and even later, when I was working on my film *Babobilicons* in Los Angeles. I love computers and discovered that I learned word processing systems almost as fast as I could read the instruction manual – and often without reading the manual at all. I worked for a company that made security systems for nuclear power plants, as well as for a company that made "missile trackers" for nuclear submarines (presumably to launch atom bombs). In addition, I worked for a synagogue in Encino, but I was fired for innocently eating a chicken sandwich on the grounds. There were many more such adventures, and I found it all a hoot.

Attempts to Get Into the Film Industry

Owing to my creative visual ability as an artist, as well as to my technical ability as a filmmaker, it seemed to some people at Cal-Arts that I should have a chance to get into the film industry. After I had graduated from Cal-Arts, and later, after I completed the award-winning film *Babobilicons*, people who believed in my abilities helped me to get some jobs working in the industry. But...I'm an Aspie, in addition to being a woman. All women have a hard time in the film industry, which is male dominated. That means not only "male dominated," i.e. that most people working in the industry are men. It also means "male fantasy dominated," in other words, expressing the male point of view. There is just no room for women in this area.

I soon gave up trying to deal with the film industry. I was offered a job doing liquid gate optical printing, but I was afraid of exposure to trichloroethylene, the "liquid" in the gate of the optical printer. Since I was considering having a baby at that time, I declined the offer. Getting into the industry by networking was impossible for me, which I knew from the very beginning. I remember a remark made by the Dean of the Film School at Cal-Arts. The Dean mentioned during a lecture that he was surprised to see so many students studying film, since so few of them had the connections to make it in the industry. I remember thinking at that time that this didn't apply to me because I was an outsider and would never "make it" in any society. For me, art and film were, and still are, a matter of spiritual survival.

Creativity makes me happy. For me, as an "Aspie," being happy is more difficult because most of the things society prizes are meaningless to me. I derive no pleasure from status, fancy clothes, ritzy cars, ocean cruises, posh dinner parties, hotels, restaurants, and so on. Perhaps that's another thing that sets me apart in the film industry. Many of the people in the industry, especially in the technical areas, work there in order to make money and think it very strange that I do the same thing for "fun." Imagine if an attorney started writing pleadings "for fun!" It would be incomprehensible!

Oh, well, I'm sixty-one years old and just finishing a feature-length art film in my computer. FOR FUN. Maybe it's just as well.

Daina's account would leave the reader in a happy mood because the writer is always aware of her strengths and weaknesses. She has found a way to be a creative and fulfilled person without the accourrements of fame and wealth. If the story were widely read, it would have a very positive impact on the public consciousness.

The next account is a true success story. A man with AS has the opportunity to work for many years in a position commensurate with his credentials.

# "Employment History" by Karl

My name is Karl. I am an adult with Asperger Syndrome(AS) who was diagnosed late in life, at the age of 44 years. I had a successful career as an electrical/electronic engineer and research scientist for over 28 years

I studied applied physics in college (B.S. Cornell University, 1976). I hold a Master's degree in electrical engineering (M.Eng. Cornell University, 1977), and one in computer science (M.S. New York University). Subsequently, I worked in the research and development laboratories of major electronics corporations.

The reason I consider my career to have been successful is that I was employed for a long period of time, and actually survived a number of layoffs before an eventual downsizing in 2005. At that time, the staff at the facility where I had worked for 25 years had been decimated to a fraction of its original size. Learning that I have AS, I came to regard this as almost miraculous when I think of the difficulties that so many people with AS have had with employment.

Like many other individuals with AS, I had the most difficulty with the interview process entailed in the employment search. This may have taken place many years ago, but my diagnosis nevertheless explained something I had always wondered about.

On a number of occasions I sent a resume to a prospective employer, who responded very rapidly and showed great interest in my credentials. After the interview, however, there was no more interest, and no job offer. In at least one of these cases I subsequently met somebody who was working for the company at the time when I interviewed. That person told me that they were desperate for people and would have hired a chimpanzee if one had applied for the job. Understandably, this had always been something of a mystery to me until I finally learned about my condition. One common trait of AS that I share is difficulty with eye contact, which interviewers generally regard as very important. Also, like many individuals with AS, I am not particularly aware of body language, and have always had unusual speech patterns.

Since I was always well-behaved, it was clear that the reasons for this difficulty involved the more subtle aspects of the interview process, rather than a blatant breach of common etiquette. In articles about job interviewing that I have read, sample questions are typically given along with "good" and "bad" responses. Such questions usually have nothing to do with the actual work for which one is interviewing, and can involve such areas as sports and entertainment. More often than not, the response that I would

have given to one of these questions fell in the category of a "bad" answer – e.g. that I had no interest in or knowledge of the area being asked about. The problem here was that my answer happened to be the truth, and that I would not have been capable of giving the "good" answer even if I had known what it was (which I would not have). It is easy to see why the interview process can be difficult for persons with AS, who are literal-minded, generally truthful, and unaware of many subtleties of human interactions.

The best things that I ever did to ensure my long-term employment prospects were to choose a career that was related to my areas of special ability and interest, to enter that field, and to find a work environment in which individuals with eccentricities were at least tolerated if not commonplace. I had always been fixated on anything electrical or mechanical since early childhood. Consequently, I majored in engineering and physics in college and became an electrical engineer. For my entire career I worked in research and development laboratories. Traditionally, research scientists had a reputation for being "unusual" and "eccentric." Thus, as a person with AS, I did not stand out as much as I would have in many typical office environments.

Another key to my employment longevity was avoidance of supervisory or managerial positions and responsibilities. Very early in my career (long before my diagnosis), I had a strong feeling that I did not want to be a manager. From everything I could see, such a job entailed the kind of activities with which I felt most uncomfortable. Moreover, supervisory positions require the kind of abilities that I possessed the least of – primarily interpersonal, communication, political, and other so-called "soft" skills.

Consequently, I made it clear that I had no aspirations to any managerial position, and — luckily — this strategy worked for me. Unfortunately, however, promotion to management is regarded in our society as the highest reward that the corporate world can bestow upon an individual. For most people, the "Peter Principle," which dictates that one is promoted until the limit of one's ability is reached, represents a "plateau" which is generally considered highly undesirable. For people with AS, however, it can be more like falling off a cliff. It is not uncommon for competent, even gifted, professionals with AS to be fired within six months of such a promotion. What is such a great reward for most people can be literally a career death sentence for someone who has AS.

In general, I tend to be either very good or very bad at most things, and there is not much middle ground between the two. This is very often the case for individuals with AS. A coping strategy that I developed was to quickly "snap up" or volunteer for any tasks or projects that were within my areas of strength, in order to avoid those that were not. The result was that I got a reputation for high-quality work, which certainly contributed to the longevity of my employment.

Probably the single most difficult aspect of the employment world for me, as for many people with AS, is workplace politics. Once again, I worked in a field, and in an environment, where many people are not politically skilled. I was therefore able to avoid politics almost entirely. I even stated that had I wanted to be a politician, I would be running for public office instead of working in a research facility. I had a few

"close calls," due to my lack of political skill in dealing with management, and due also to my sometimes-inappropriate personal demeanor. Nevertheless, I was always able to emerge with my reputation intact owing to the successful completion of my technical tasks.

Sadly, a common trait in many employment advertisements of the past two decades has been the statement that "strong interpersonal and communications skills are required." Whenever I see this, I translate it as "persons with autism spectrum disorders need not apply," as these are the areas where we have the most difficulty. The requirement for "communication skills" does not simply refer to correct grammatical usage of the English language. These skills involve interaction with colleagues and superiors.

In conclusion, I have come to realize that most of the challenges I have faced in my employment history, as well as many of the successes I have enjoyed, were due in no small part to this condition known as Asperger's Syndrome. I have suffered my entire life with it, but I was not aware of the condition until fairly late in my adulthood. The successes I enjoyed can simply be attributed to good fortune, such as my entering the job market at a time when there was a great demand for people with my educational background. It was precisely the particular strengths so common in people with AS that proved of greatest benefit to me in the course of my career.

### "Pink Balloons" by Louise

The essay submitted by Louise is the saddest account I have ever read. This woman has an undergraduate degree in early childhood education from Queens College. Yet, despite her rich background, between 1997 and 2008, she lost job after job in facilities for special needs children. Louise was not diagnosed with Asperger's Syndrome until she was 56 years old. When she comes to GRASP meetings, she radiates despair—with good reason.

Louise's essay does not lend itself to presentation in the context of this book; however, I can summarize the four most severe obstacles she has encountered. First of all, her employers were all Black women from the Caribbean islands. Louise, as a middleaged white Jewish woman, had one big strike against her. This was a clear case of reverse racism.

The second obstacle was Louise's higher education and her outstanding knowledge of her field. The women who were above her in rank clearly resented that Louise had a background superior to theirs, and that the children responded very well to her. The third obstacle was the typical Asperger's lack of "street smarts." Louise showed openly that she disagreed with her superiors, and she went against their orders. Many of us on the spectrum are too honest to be "political," i.e. to simply obey orders even when we know that the superior is wrong.

Finally, the fourth obstacle Louise faced was a learning disability, which precluded her further education in a graduate program. Learning disabilities often go hand in hand with Asperger's Syndrome and stand in the way of fulfilling our potential.

Louise was learning computer skills when I first met her. I spoke to her social worker, who often came to the meetings with Louise. I begged the social worker to try to find Louise a position with special needs children. Louise claims that she cannot find any job anywhere doing what she loves.

There are few people who are equipped with the knowledge and, yes, the empathy for special needs children that Louise has. She truly loves the children and has both the intelligence and the background to work in her profession. I hope that she finds a way to fulfill herself and to overcome some of the obstacles caused, in no small part, by her own behavior.

Reading the various essays on employment of people with Asperger's Syndrome could evoke a mixed impact on the public consciousness. On the one hand, the reader can see the despair and frustration involved in finding and retaining employment when that employee has Asperger's Syndrome. That would surely move some to compassion. On the other hand, the reader should admire the pluck and optimism shown by persons with Asperger's Syndrome who stumble and fall, yet pick themselves up to try again until they finally succeed.

I now turn to the most powerful vehicle for impacting public consciousness of Asperger's Syndrome: The Media.

# 3. Asperger's Syndrome and the Media

First I will address various articles on the subject of AS and their potential impact on the public consciousness.

I will continue with the novel by Jodi Picoult entitled *House Rules*, which depicts the challenges faced by a mother of a boy with Asperger's Syndrome, and also the stereotype of the violent male with Asperger's.

Next I will turn to four films, which expressly designate the presence of AS, and will be discussed as to their impact on public consciousness. The films are *Mozart* and the Whale, Ben X, Adam, and Mary and Max. The HBO film Temple Grandin will be discussed because, despite the autism diagnosis, Grandin in many ways fulfills the criteria for Asperger's Syndrome, and because this brilliant professor has changed public perception of those of us on the autism spectrum.

A discussion of the portrayal of Asperger's Syndrome on reality television shows follows. A blog commenting on the depiction of Asperger's Syndrome in the *Dr. Phil Show* will receive significant attention because of the show's inaccurate and appalling portrayal of Asperger's Syndrome, as well as due to the potentially deleterious impact this widely-viewed program probably had on the public consciousness. In addition, an article on the contestant with AS in *America's Next Top Model* will provide an alternative and compassionate depiction of a person with Asperger's Syndrome.

Television fictional series for adults will furnish the final area of discussion. Some of these series have had a potentially positive impact on the viewer, whereas others have potentially had the very opposite effect. The level of exposure of these series is a major factor. The hit series Law and Order (including the offshoots Special Victims Unit and Criminal Intent) was viewed by millions. In addition, a summer series entitled Flashpoint included a powerful episode dealing with a boy with AS which merits a brief discussion. Each of these series was also researched on the internet with regard to comments by newspaper critics or in blogs.

# Articles on Asperger's Syndrome

# Lawrence Osborne, "The Little Professor Syndrome"

Asperger's Syndrome entered the public consciousness with Lawrence Osborne's article published in the June 18, 2000 edition of the *New York Times Magazine*. Suddenly parents could find a reason for their children's oddness. The diagnosis, until the publication of Osborne's article known chiefly to mental health professionals, became accessible to a broad spectrum of American readers.

The author described his observations of, and interaction with, Asa, who is a young boy with AS. The author also spoke with Asa's father, Phil Snyder. Osborne's initial contact with Asa occurred in the Special Education School associated with the New York League for Early Learning. In Lauren Cacchabaude's class, Osborne found that despite the outward similarity to most classes, there was something "off" in the group of pupils. The author explained that Asperger's Syndrome is defined by the Learning Disabilities Association of America as "a severe developmental disorder characterized by major difficulties in social interaction and unusual patterns of interest and behavior." Osborne added that, unlike in autism, the child with AS is not mute or incapacitated. In fact, their extremely large vocabulary makes them appear to be gifted rather than disabled. Osborne cited Dr. Richard Perry 's finding that because these children "cannot decipher basic visual social signals, they are seen as "emotionally disturbed."

Osborne then met with Jeanne Angus, Director of the New York League School, who dropped in on the classroom. Angus provided Osborne with further enlightenment, saying that these children are normal in many ways, and "even sweet." They are also "amazingly precocious. But look closer and you'll see cracks. Many of them have appalling difficulties in the regular school system. Everything has to be taught to them."

Osborne then listed features common to AS children such as "temper tantrums and erratic behavior that can unnerve even the most strong-willed teachers." Asa, for example, would roll on the floor when he first entered the class, in order to get the feel of the floor's texture. He had no idea that this behavior is inappropriate. The "anarchic solitude is reinforced by obsessive interests." An example of such interests is a fixation with tornadoes. The bizarre fixations of AS children include memorizing entire television shows and reciting them over and over. They talk like "little professors."

Phil expressed to Osborne his belief that the ability of an AS person to synthesize information in novel ways would ultimately benefit his son. "Society will actually become more and more dependent on people with Asperger's to usher it through the difficulties ahead."

After many unsuccessful attempts to get Asa into an appropriate school, Asa's parents discovered the New York League School, where the aim was not to drum all Asperger's Syndrome characteristics out of the children's heads. Rather, the goal was to help them control the more outwardly disadvantageous characteristics in order for them to succeed in the social jungle.

Osborne's article was more than a pioneering media work on AS. The author did not sugarcoat the syndrome, fully recognizing the deficits. However, children, as well as the adults, with Asperger's Syndrome, emerge in this article as sometimes exasperating, but more often oddly endearing. What is most important, Lawrence Osborne opened the door to the general public for an accessible discourse on Asperger's Syndrome. Osborne's article not only impacted the public consciousness. The article also enabled parents of AS children to understand the behaviors that had previously mystified them, and then to seek appropriate counseling and education.

# Maia Szalavitz, "Defining Autism: Gifted? Autistic? Or Just Quirky?"

Whether the label of Asperger's Syndrome is a positive or negative factor in people's lives is explored by Maia Szalavitz in her article, which appeared in the *Washington Post* issue of February 27, 2007.

Szalavitz interviewed Phil Schwarz, who was diagnosed when he was in his late thirties—right after his son was diagnosed with High Functioning Autism. Schwarz found the diagnosis "paradoxically liberating." He describe being called "gifted" as a child, but his struggle with depression resulted in his not living up to the promise of his past. He was sensitive to loud noises and bright lights. Schwarz termed his conversational style "syncopated." It was all related. Upon being diagnosed, he saw life through a new lens and became the Vice President of the Asperger's Association of New England (AANE). Schwarz said: "It's not the label that's the problem, but the baggage associated with it." He concluded: "The sun is a metaphor for the only thing that arrests our attention—the painful burning intensity of the disability, that's your world. But of course there's more to it."

Author Szalavitz stated that many people dislike the label "Asperger's Syndrome," and they feel it is better to be odd than broken. Nevertheless, she added that the label is not always a disadvantage and is often sought out by parents who want to obtain for their children extra time on school tests or reimbursement for treatment. Szalavitz asserted that from 1987 to 1996, the number of medication prescriptions for children

grew threefold. Moreover, the author noted, the label resolves ambiguity with which many people are uncomfortable.

Szalavitz's article also included views of adolescents with AS. Dan Grover, age 18 and a college student in Boston, co-founded *WrongPlanet.net*. This is a site for teens on the autistic spectrum. Grover opined that the label was both good and bad. It explains much, but it can end up being a "self-fulfilling prophecy." Being aware of the traits can magnify them. Grover stated that when some people know of his diagnosis, they distance themselves from him. David Dunnington, age 18 and from Yorktown, Indiana, told the author via e-mail that his diagnosis initially upset him. However, he added that he now values his photographic memory and reasoning skills associated with AS, even though adults tend to treat him like a child.

The author also spoke with Kathleen Seidel, the proprietor of *Neurodiversity.com Website*. This is a resource for autism information, "honoring the variety of human wiring." Seidel is also the mother of a child on the autistic spectrum. Seidel highlights the strengths of autism spectrum conditions as well as the problems. She believes that one should respect the desire of a person diagnosed to disclose or not to disclose. Seidel deplores the attempts to link autism with mercury poisoning because it makes the autistic person feel "contaminated." Thus, a child's parent may see the child as a "toxic waste dump."

Szalawitz concluded her article with the suggestion that parents and teachers should see beyond the "blazing brightness of any label and into the individuality and potential of the person in front of them."

# Emine Saner, "It Is Not a Disease, It Is a Way of Life"

Emine Saner's article appeared on August 7, 2009 in the UK newspaper *The Guardian*. The article focuses on the "cure debate."

Saner interviewed Gareth Nelson who calls himself an "Aspie" and was diagnosed with AS when he was 14 years old. He appeared for his interview dressed all in black and looked young and "nervy." He did not return Saner's smile. Nelson views his lack of social skills, as well as poor organizational skills, as the only negative AS traits he has. Saner noted that Nelson prefers to socialize on line. Saner also spoke with Nelson and his wife Amy, who also has AS. The couple leads UK's autism rights movement in a group called "Aspies for Freedom" (AFF). Both the Nelsons see no need to cure autism because the condition is not "purely negative." They point out that many black people are at risk for sickle cell anemia, but there is no intent to cure "blackness." The couple views the autism movement as tantamount to the civil rights and gay movements.

The author noted that not everyone on the spectrum shares the Nelson's views. Larry Arnold is the first autistic to join the Board of the National Autistic Society (NAS). Arnold opines that the people in Aspies for Freedom are "politically naïve." Opposed to separatism, he feels that there should be universal anti-discrimination laws. According to Arnold, autism is a part of neurodiversity, and the handicap is created by society rather than the condition. Arnold deplores the pitying attitude at the root of the movement to raise funds "for research which wants to eliminate us from the planet." Arnold adds, "I'm for valuing every level on the autistic spectrum, it doesn't matter how able or unable you are to carry out 'normal' functions that are dictated by society. "

Saner quoted Professor Simon Baron-Cohen, the director of the Autism Research Centre at Cambridge (UK), as saying, "nobody would dispute the place for interventions that alleviate areas of difficulty, while leaving the areas of strength untouched. But to talk about a 'cure for autism' is a sledge-hammer approach."

I consider Emine Saner's article among the most powerful as far as its potential to change public consciousness. Stereotypes of autistics are challenged and hope for the future of our population is made manifest.

In spite the assertions of various experts in the field of autism, people with Asperger's Syndrome are not always single and alone. Two articles on AS reveal that people with our condition can, and do, find spouses and have families. In a third article a concern is raised that we AS people may be "multiplying" and creating an epidemic. This is because so many high-functioning men and women with Asperger's are marrying and having children.

# Suzanne Leigh, "A Long Shadow Lifted in Asperger's in Adults"

Suzanne Leigh, in a Special for *USA Today* dated July 23, 2007, quoted various mental health professionals with regard to their views on AS, and on the capacity of persons with AS to have intimate relationships.

Leigh quoted research scientist Katherine Tsatsanis of the Yale Developmental Disabilities Clinic. Tsatsanis asserted that "almost by definition, an Asperger's person would not form an intimate relationship, get married and have children. They don't form connections. The desires, the drive, and the social knowledge is lacking."

Leigh also quoted psychologist Kathy Marshack, who maintained, "experts who say Asperger's adults don't marry or have children either have their heads stuck in the sand or do not believe many have learned to compensate for their deficits." Marshack told Leigh that her late mother had AS. Marshack came into contact with the Asperger's diagnosis when she treated spouses and adult children of persons with Asperger's Syndrome. These clients suffered depression and low self esteem due to the coldness and egocentricity manifested by the adults in their lives who have AS. Despite Marshack's

experience with such clients, she does not share the views of the "experts," who are convinced that AS adults by nature do not want relationships.

The author made reference to the author of *Pretending to Be Normal*, Liane Holliday Willey. Despite a childhood desire to avoid her peers, Holliday Willey married and had three children. Moreover, Leigh noted the existence of anecdotal evidence that there is a burgeoning subculture of adults with AS who are on dating sites and chat rooms, as well as belonging to advocacy groups.

Leigh also spoke with William Loughman of Berkeley, California. Loughman, at age 74, was a retired director of a hospital cytogenetics laboratory. He also had AS. Although his first marriage had failed after ten years, his second marriage lasted forty years. Loughman recalled that he and his second wife went through some turbulence. However, he said that their lives were now peaceful. Leigh noted that Loughman was also the grandfather of six children.

Suzanne Leigh's article casts serious doubt on the depictions of Asperger's adults as not desiring close relationships. In view of the fact that these articles were published in widely-read newspapers, their power to impact positively on the public consciousness is undeniable.

The next article raises the question whether autism spectrum cases are on the rise due to increasing marriage and reproduction among AS persons. The article also addresses the question of whether this trend is a good or a bad thing.

### Steve Silberman, "The Geek Syndrome"

Steve Silberman's article appeared in *Wired.com* on August 28, 2008. The piece dramatically informed the public: "Autism – and its milder cousin Asperger's syndrome – is surging among the children of Silicon Valley. Are math- and- tech genes to blame?"

The author explained that the surge in the number of kids diagnosed with autism is causing concern. From 1993 to 1999, the number of cases doubled. In 2001 there were 15, 441 cases. By 2008 there were 7 new cases per day being diagnosed with autism. According to the author, the exponential increase in cases in Santa Clara County, which is the location of Silicon Valley, cannot be explained simply by the availability of better diagnostic tools.

Silberman noted that there is a joke in the Information Technology industry that hard-core programmers in strongholds such as Intel come to work early and leave late, and "are residing somewhere in Asperger's domain." Bill Gates has been regularly diagnosed in the press as having AS, due to "single-minded focus on technical minutiae, rocking motions, and flat tone of voice, all suggestive of an adult with some trace of the disorder." Silberman commented that "in the geek warrens of engineering and R&D, social graces are besides the point. You can be as off-the-wall as you want to be, but

if your code is bulletproof, no one is going to point out that you've been wearing the same shirt for two weeks."

According to Silberman, as more women enter the IT industry, men, who once would have had no hope of finding a kindred spirit, find that Ms. Right is in the next cubicle hacking Perl scripts. There is a very provocative hypothesis that may explain the rise of autism spectrum disorders in communities like Silicon Valley. That hypothesis is termed Assortive Mating.

The author drew the reader's attention to the fact that research has revealed that genetics has an impact on whether a child is born on the spectrum. If one twin is autistic, there is a 90% chance that the other twin will also be autistic. Environmental factors may also play a role in the rising numbers of children diagnosed with autism. Multiple genes may make a child more susceptible to an environmental trigger. Increased reproduction among people carrying those genes may result in increased "genetic loading" in successive generations.

Silberman admonished: "The chilling possibility is that what's happening now is the first proof that the genes responsible for bestowing certain special gifts on slightly autistic adults – the very abilities that made them dreamers and architects of our technological future – are capable of bringing a plague down on the best minds of the next generation." The author concluded the admonition with the observation that more and more IT employees are encountering each other in waiting rooms of clinics, embarking on a journey with their autistic children that will last the rest of their lives.

Silberman quoted Dan Geschwind, director of the neurogenetics lab at UCLA, who maintained that certain kinds of excellence might require more than various modes of thinking. It may require a different kind of brain. Geschwind observed: "Autism gets to fundamental issues of how we view talents and disabilities. The flip side of dyslexia is enhanced abilities in math and architecture. There may be an aspect of this going on with autism and assortive mating in places like Silicon Valley. In the parents who carry a few of these genes, they're a good thing. In the kids, who carry too many, it's very bad."

The author also spoke to University of California-San Francisco neurologist Kirk Wilhelmsen, who maintained: "It may be that autistic people are essentially different from 'normal' people, and that it is precisely those differences that make them invaluable to the ongoing evolution of the human race...The healthiest state for a gene pool is diversity of things that might be good." Wilhelmsen also claimed that to eliminate genes for thinks like autism would be "disastrous."

For me, reading Steve Silberman's article was both thrilling and horrifying. It is thrilling that we who live with AS can find meaningful and fulfilling lives with spouses and children. It is horrifying to think of autism as a "plague." The next step would be to designate all disabilities as a "plague" and to seek to abort any fetus with a chance of disability. What would the "final solution" be? To exterminate, or to use for experimental purposes, autistics and all other persons whose disabilities disturb others and cost society money? That ship has sailed! Hitler and his followers exterminated

not only Jews, but the disabled as well. Despite the very negative aspects contained therein, Silberman's article debunks the widely-held belief that people with AS are doomed to a lifetime of loneliness.

On the whole, the above-discussed articles on Asperger's Syndrome are positive as to their impact on the public consciousness. The articles reveal that we who have AS may not only marry and have children, but also pass great talents along to our offspring.

The article by Silberman might raise in the reader's mind a major ethical question: Should we who have AS procreate if we know we can pass on the predisposition to AS? If we who have AS should not procreate, that would have to apply to people with mood disorders, schizophrenia, Huntington's Disease, epilepsy, as well as to all other persons with possibly inherited disorders. That is a slippery slope of which we must be aware.

Asperger's Syndrome is thought to implicate more than one gene, making prevention more complicated. As I observed above, the medical professionals during the Nazi era already dealt with disabled persons in a way that should strike terror in the hearts of the Asperger's population. Members of the public reading the above-discussed articles will most likely recall the fear-provoking material more vividly than the reassuring information.

At this juncture, the discussion of articles on AS is concluded and the next topic is the depiction of Asperger's Syndrome in a best-selling novel.

#### Jodi Picoult, House Rules

This novel is a mystery of which I shall reveal as little as possible. Jacob Hunt, eighteen years old, has Asperger's Syndrome. He lives with his mother Emma, who is separated from her husband. Emma has another son named Theo. This young man, who breaks into people's homes, evinces signs of being a sociopath.

The Hunt home centers around Jacob's intense likes and dislikes. Clothes must be ordered by color, and food must be a different color on different days of the week. Although Jacob has tantrums and other behavioral issues, he is able to go to a high school, where he has special accommodations such as a room to calm down. The highlight of Jacob's life is his interaction with his social skills tutor. He has a crush on her as well.

One day the tutor is found murdered. Jacob is the prime suspect because he was seen having an altercation with her in a restaurant. Also contributing to the police's suspicion of Jacob's guilt is his passion for crime scenes, where he often shows up to help the police with his arcane knowledge. The police investigation and the trial tear the Hunt family apart. Despite the link between AS and violent crime, which Picoult's novel seems to initially strengthen, the story ultimately reveals that this link is one forged by the bias of the public towards Jacob due to his Asperger's Syndrome.

Picoult's novel has the power to impact positively on the public consciousness because AS is made understandable, and the stigma associated with it is ultimately challenged. There was widespread coverage of the book in newspaper reviews and *House Rules* was number one on the *New York Times Bestseller List* when the book first appeared. It continues to be a bestseller. There were many reviews, most very positive. I shall mention just two of them, because they were in widely-read newspapers such as *USA Today* and the *Washington Post* Book World. Since Picoult's novel, *My Sister's Keeper*, was made into a film, I am convinced that there will soon be a film version of *House Rules*. This film will have the potential to impact the public consciousness as no work of fiction on Asperger's Syndrome has to date.

Having concluded the discussion of the one novel on Asperger's Syndrome, I will proceed to a discussion of films on the subject.

# Films on Asperger's Syndrome

Mozart and the Whale, Ben X, Adam, and Mary and Max are the four films in which Asperger's Syndrome is specifically designated as the characters' diagnosis. Although diagnosed autistic, rather than with Asperger's Syndrome, Temple Grandin and her biography inspired a recently-released HBO film entitled Temple Grandin. This film impacted on the public consciousness because it was reviewed in major newspapers.

# $Mozart \ and \ the \ Whale \ (2006)$

The film *Mozart and the Whale* is described in the Introduction to Mark Osteen's text *Autism and Representation* as providing "an example of a resourceful and courageous person who happens to have a disability, usually enacted by a well-known performer."

Osteen, however, waxed more critical in the latter section of his evaluation of the film. He stated: "The film initially seems to transcend trite approaches (having savant skills or stereotypical autistic behavior). However, *Mozart and the Whale* ultimately falls victim to trite approaches." I viewed *Mozart and the Whale* and disagree with Osteen's opinion of the film. Despite some weaknesses, I found this film to be educational and very moving.

The film begins with the male protagonist, an attractive man of about thirty named Donald Morton, driving passengers in a cab. He is talking incessantly about how he was fired from several jobs. Within minutes Donald loses control of the taxi and crashes into a store display of flower stalls. He is, once again, fired.

Undaunted, Donald grabs large bags from the cab and heads toward his autism support group. While he is unpacking the bags, the viewer sees one woman laughing constantly at inappropriate times. A fragile young girl moans that everyone "uses autistics." Donald's best friend and sidekick, an aspiring writer named Gregory, upbraids Donald for being late to group. Then he informs Donald that they are all going to the park. Gregory adds that a new member named Isabelle Sorenson has signed in on the attendance sheet.

At the park Donald meets the female protagonist Isabelle. She is also about thirty and very pretty, albeit dressed in a ditsy way. Her demeanor is giddy and her laugh is loud, like a bark. During this park scene, Donald and Isabelle discover how similar they are. For example, Isabelle (called Izzie by Donald) recalls how as a child she heard the phrase "broke a record." Then she literally broke a vinyl record. Donald identifies with

her, saying he also takes everything literally. Then they discuss their love for animals. Isabelle notes, "animals are different, you can't teach them cruelty." Donald agrees and observes, "you can't control people, but you can count on numbers." Donald is a savant with numbers who also uses numbers to calm himself when stressed. He tells Isabelle that with Asperger's you want to be with people, but you are clueless as to how to achieve this. The conversation becomes more intimate when Isabelle reveals that she was raped, and that she let the man do it because she thought the sex would make him love her. Isabelle then leaves the park because she has to feed her animals.

When Donald and Isabelle next go to the group, Gregory comments that Donald and Isabelle are different because they have Asperger's and the rest of the group members are autistic. Donald and Isabelle plan to meet for lunch the next day.

Initially it appears that Isabelle is neurotypical because she has steady employment in a beauty parlor, where she gets along with co-workers and customers. This belies the stereotype about people with Asperger's being unable to hold a job. Moreover, at the group Isabelle speaks compassionately to a young girl who is dealing with cancer in her family. Again, the stereotype of people with AS is challenged, because Isabelle evinces empathy.

The next day Donald and Isabelle are at the zoo, where Isabelle communicates with a chimpanzee. People around them watch and laugh. Donald counts the minutes in a year that he doesn't eat breakfast. He says, "I can't stop." Isabelle adds, "neither can I. I'm autistic." (The viewer may note that Isabelle does not distinguish her Asperger's from autism.) She adds that she cannot censor herself; she just says whatever she thinks.

On Halloween Donald and Isabelle decide to go to the mall. Isabelle is dressed in a beautiful Mozart costume and Donald has on a whale costume. He notes ruefully, "all my life I kinda felt that I was on the sidelines." During this scene Isabelle tells Donald that she loses control of herself when she hears the noise of metal hitting an object. Donald is oblivious to this communication, which subsequently proves to be significant.

Donald tells Isabelle that they will go to the amusement park. Then comes the moment when Isabelle normally loses friends: Donald leads her to the ring toss and the sound of the metal drives her into a meltdown. The onlookers see what appears to be an exhibit more dramatic than anything at the amusement park. Donald, however, does not end the relationship. Isabelle is amazed that Donald still wants to be with her.

Isabelle completely transforms Donald's life. She tells him that he brings together lonely people, but is not paid for his work. Donald replies, "but I am lonely, too." Isabelle manages to obtain for Donald a position at the medical center where her psychiatrist works. Here, he can use his amazing savant skills with numbers. His boss tells him that they actually seek employees with special needs.

Once Donald is working, Isabelle convinces him to move into a cottage with her. They would not pay more than their two apartments cost together. Initially, things go well.

A major crisis in Donald's and Isabelle's relationship occurs when Donald invites his boss for dinner. He asks Isabelle to "be nice." Infuriated, Isabelle behaves outrageously. Donald confronts Isabelle, who accuses him of craving to be "normal." That, she asserts, is the difference between them. She throws Donald out of the cottage but later calls him and says she is not angry any more.

Donald moves in with Gregory who tells him, "in the group you are a god, but with Isabelle you don't come off so well. "Soon afterward, Isabelle's rabbit Bongo dies. When Donald comes to comfort her, she tells him that she wants to have him just as her friend. Donald agrees to the arrangement. Despite Gregory's warning, however, he still has hope for love and marriage with Isabelle.

Another crisis occurs when Donald invites Isabelle to an elegant restaurant and tells her that he thinks she really wants to marry him. Isabelle has a severe meltdown and exits the restaurant screaming, "I don't want you to save me. I just want to be left alone." She attempts suicide. Donald finds her and brings her to the hospital. The group is there as well. Isabelle's psychiatrist tells Donald, "Asperger's is a funny animal." She forbids Donald to contact Isabelle again. It is at this juncture, when the whole group is at the hospital, that the viewing public can see that people on the autistic spectrum can be caring, compassionate, and, even empathetic.

Donald leaves Isabelle alone and finds comfort in the support of the group he started. Then he sees Isabelle on a bus and chases after her. She asks him why he did not call. He explains that he thought it would be harmful to her. They try again to make their relationship work and continue their relationship with the support group. Even with their peculiarities, they all form a united family.

I believe that *Mozart and the Whale* had a positive impact on viewers. Both the actors, Josh Hartnett and Radha Mitchell, made the characters very appealing. This film, despite its flaws, humanized Asperger's and made it accessible to the public consciousness. I would have preferred it if persons with Asperger's were not portrayed as being superior to those with autism. This portrayal only serves to strengthen the stereotype that a person with Asperger's Syndrome is high functioning while people with autism are low functioning. As far as the media response is concerned, I felt that they did not do justice to the film. The reviewer of *Variety Film*, a widely-read magazine, considered the film full of stereotypes.. The less widely-read *DVD Clinic* totally degraded *Mozart and the Whale*. Precisely because, in my opinion, the reviews treated the film unfairly, I gave extensive coverage to it.

My discussion of  $Ben\ X$  will be brief. I found the film to be unsatisfactory; however, I was pleased to at least see some enlightening material on Asperger's Syndrome.

# Ben X (2008)

Ben, a student who has Asperger's Syndrome, lives at home with his parents. (The Belgian director, however, labels Ben as autistic.) Ben spends all his free time lost in the fantasy of on-line gaming. At school the other students ridicule him. He does have as a friend one sympathetic female fellow student. The crisis occurs when the other students' cruelty causes Ben to reach the breaking point. He decides to stage his own suicide to make his tormentors aware of the impact their abuse has on him. His ruse works. The school's staff and students evince compassion for Ben and remorse for their conduct towards him. The ending has a surprise twist.

I read on line that there were 36 reviews of the film. 24 were poor and 12 good. The reviewer in the *Evening Standard* noted that writer-director Nic Balthazar's stage version of *Ben X* had been successful and had even won awards, Nonetheless, the critic found the film too convoluted, and also observed it was hard to distinguish where fantasy ended and reality began. I agree with this reviewer. What did impress me favorably was the narrow preoccupation with gaming and the social awkwardness evinced by the Asperger's protagonist.

Seeing the next film evoked in me a very different reaction. When I went with the GRASP support group members to see *Adam*, I experienced the greatest relief. Here, at last, was a realistic and sensitive depiction of a person with Asperger's Syndrome. Our group was given free passes to the showing before the actual premiere of the film.

# Adam (2009)

When the film begins, Adam Raki has just lost his father. The young man eats the same food day after day. Moreover, he is terrified at the prospect of leaving his apartment. Adam has a job as an engineer, but he is terminated due to an inability to meet the standards of his employer. Adam has one good friend, an African American named Harlan who had been close to Adam's father. To this man, Adam talks incessantly about his passion (astronomy). Although Harlan sighs with boredom, Adam cannot read social signals. How well this will resonate with all of us who have AS!

Adam's life is soon turned upside down by Beth Buchwald, at eacher of tiny children. Typically unaware of another person's needs, Adam never thinks of helping Beth carry heavy bags. As the plot continues, Adam and Beth fall in love. Beth learns about Adam's Asperger's Syndrome and is compassionate towards him. She forgives him even after he has had a severe tantrum in her presence.

Problems arise first when Adam meets Beth's parents. While her mother reacts positively to Adam, the father, Marty Buchwald, feels that Adam is not good enough for his daughter. He has no tolerance for Adam's disability.

A crisis occurs when Adam is chosen for a job that is perfect for him, except that he must move to California. When he tells Beth that he will need her to take care of him,

she refuses to go to California to be his "mother." Adam, however, goes to California by himself and does well in his new position.

I wept with joy to see, at last, a film, which honestly depicts the weaknesses and strengths of those of us on the autistic spectrum. *Adam* merits being shown in schools and at places of work.

Not surprisingly, Adam won an award (the Alfred P. Sloan Prize) at the Sundance Film Festival. Positive reviews of Adam appeared in widely-read newspapers, The New York Times, the L.A. Daily News, and in the Sundance Film Festival 2009 News. Although the general public was probably not impacted by the film, many more educated viewers surely were.

# Mary and Max (2009)

Mary and Max is a "clayography," using clay figures with actors' voices. It tells the story of a 20-year pen pal relationship. The story begins when Mary, an eight-year-old girl living in a suburb outside of Melbourne, Australia, picks Max's name out of a New York City telephone book. Lonely and ostracized by her peers because she has a large brown spot on her face, Mary writes Max a letter.

Max is an obese, depressive Jewish man living in the chaos of New York City. Max also has Asperger's Syndrome. He takes pride in being the inventor of the chocolate hotdog. His only activity is a weekly meeting of Overeater's Anonymous. Uncomfortable interacting with people face to face, Max responds to Mary's letter, and so the relationship begins. This film deals with the alcoholism of Mary's mother, to which Mary later falls prey, and with Max's compulsive eating and depression. The two pen pals have a brief crisis in their relationship when Mary, a graduate student, writes a book that offends Max. However, Mary and Max reconcile. At the end of the film Mary comes to visit Max in New York City. The conclusion of the film is unexpected.

I viewed the film and was unhappy with it because it strengthened the stereotype of the lonely, pathetic Asperger's male. However, it was moving in that it showed the potential of deep friendship between a person on the spectrum and a neurotypical.

Although the reviews were basically positive, Max's Asperger's Syndrome was not significantly addressed, or not addressed at all

The Sundance Review Max mentioned Max as having Asperger's Syndrome only once, in context with being overweight, old, and anxious. In Variety the critic mentioned that Max's professional failures and lack of relationships are explained by the fact that Max has Asperger Syndrome.

The reviews I found did not do the Asperger's community any service of enlightenment. Nonetheless, I believe that the broad publicity the Sundance Festival enjoys, as well as the extensive exposure the viewers had of the film, may have resulted in an impact on the public consciousness with regard to AS. As depressing as Max is, he surely would have stirred compassion in many viewers

# Temple Grandin (2010)

On February 6, 2010, the HBO film on Dr. Temple Grandin's life was broadcast. I viewed the DVD of this film and found it inspiring and remarkable in every way. In fact, I believe that it surpassed the film *A Beautiful Mind*, based on the life of math genius and Nobel Prize recipient John Forbes Nash. It appears that I am not alone in my high opinion of this film, since it won numerous Emmy awards at the August 29, 2010 ceremony.

Claire Danes's performance was amazing in how she captured the voice and mannerisms of Temple Grandin. What thrilled me most was the college graduation scene in which Temple sings "You'll Never Walk Alone" from *Carousel*. Recalling my years of peer ostracism, I sobbed aloud in my apartment during the scenes in which Temple is ridiculed by her schoolmates.

Her grit and determination in fighting for access to the male-dominated world of animal sciences and cattle ranching filled me with awe. Temple Grandin achieved all this during the 1960s and 70s when being disabled, and female as well, represented seemingly impossible hurdles. The film is also a work of art in that it depicted the way Temple Grandin saw things in pictures. She was portrayed by Danes as a genius and a savant, but also as a person full of quirks and subject to frightening meltdowns. The film *Temple Grandin* revealed the importance of Temple's allies, starting with her mother, who told her, "you are different but not less." The support Temple Grandin experienced continued with her mentor in boarding school, and also with her many friends and employers. Seeing the film made me feel honored to have had the opportunity to speak to this valiant and remarkable woman.

This HBO film received over 12,000 reviews from both magazine critics and blog writers. The film was reviewed by major newspapers such as *The New York Times*, the *New York Daily News*, the *New York Post*, *The Washington Post*, the *Hollywood Reporter*, and *The Los Angeles Times*. All these newspapers gave the film unqualified excellent reviews.

It is of special relevance that the TV Guide reviewer praised the HBO film and Claire Danes's performance. In addition, the critic added background information not found in other reviews. Specifically, Dr. Temple Grandin herself was closely involved with the making of the film. Moreover, Grandin was responsible for a major breakthrough involving the autistic son of Emily Gerson Saines, the executive producer who nurtured the HBO film. The many readers of TV Guide would probably have been touched by this anecdote and more likely to view the film. Once these viewers saw the film, it is likely that the powerful story would impact their consciousness.

The five films discussed above all had the potential to have a positive impact on the public consciousness. *Temple Grandin*, clearly, must have had the most positive impact of all. The protagonist in *Adam* has fears and quirks. The autistic characters in *Mozart and the Whale* are nevertheless the "family" of the two Asperger's protagonists. The film *Ben X* made a contribution towards impacting the public consciousness regarding

the devastating effects of ridicule upon a young person with Asperger's. *Mary and Max* was valuable because it portrayed a lasting and meaningful relationship between a person with Asperger's Syndrome and a neurotypical.

With the segment on films concluded, the next section of this book will deal with the depiction of Asperger's Syndrome on television. First, reality television will be discussed. *The Dr. Phil Show* represents an extremely negative, as well as harmful, depiction of a teenage boy with AS. *America's Next Top Model*, on the other hand, represents an enlightening and positive depiction of a young woman with AS.

Secondly, fictional characters on television series, who are designated as having Asperger's Syndrome will be discussed.

# Reality Television Shows

# The Dr. Phil Show, "Extreme Disorders (2006)

I myself did not see this *Dr. Phil* episode, which aired on January 17, 2006 and dealt with Asperger's Syndrome. However, I heard a great deal about it and did view a snippet of it on the internet. I believe that Dr. Phil McGraw dealt the AS population its most devastating blow. The daily show is known to be widely viewed, and Dr. Phil's title cloaks him in the mantle of expertise.

My information on the episode stems from a blog entitled *Autism's Edges* published by "Mothersvox." The publisher of the blog is a New York City schoolteacher, an activist, scholar, and the mother of an autistic child. In her entry dated January 18, 2006 the *Dr. Phil* episode on Asperger's Syndrome was discussed.

In the blog the author stated that it is violence that gave the segment on AS its "pizzazz." The lead-in is shown in jagged jumping letters spelling 'Extreme Disorders,'" against a stormy sky with sudden flashes of lightning. The subject, teenager Alex, is introduced with his parents. The boy is described as "a ticking time bomb." He has episodes of violent rage. Dr. Phil hears from Alex's parents that when Alex was just ten years old he could throw his father across the room during an episode. Alex's parents are terrified of their own son. Alex's father does not tell his wife until they are on *Dr. Phil* that he hides knives and hammers, as well as medications, from their son. According to "Mothersvox, "this information resonates with people who "live at the edges of autism or in its midst."

However, at issue is not Alex's violence towards his parents, but rather towards his schoolmates. The seemingly personable young man tells the television audience that he is called "retard" at school and that he has "bouts of anger and rage." Alex's friends think he is very nice, but if he is egged on and his stress level is high, he "will get mad and may hurt somebody."

Dr. Phil introduces as his "expert" a neurologist who shows the audience a functional magnetic resonance image (FMRI), depicting a brain with abnormal blood flow and brain activity in the frontal and temporal lobes. This is not Alex's brain, so Dr. Phil jokingly suggests taking an FMRI of Alex's brain for him to show the kids at school. Dr. Phil claims that the FMRI is a "revolutionary new treatment," which could help Alex. However, at no point in the episode does Dr. Phil discuss any treatment options for Alex.

In the small clip of the show that I viewed, Alex is asked if he can feel a "tantrum coming on." He replies: "I will start getting a headache. I will start making a fist. I'll just feel my whole body shaking at times...I do not realize what's going on around me at all."

After seeing this clip, I wanted to ask, "gee, Dr. Phil, why did you not check with your expert neurologist whether what Alex described is a symptom of AS or of another neurological disorder?" Dr. Phil never discussed the issue of any co-occurring disorders, which could explain Alex's "tantrums."

The "Mothersvox" blog received myriad responses to the entry on the January 17, 2006 episode of *Dr. Phil.* Three of these bloggers are well worth quoting here.

"Dr. Phil had such an opportunity to educate the masses and he just absolutely blew it by going for the shock value..."

"The TV producers are spouting stereotypes and inciting bigotry against a minority group for no reason other than to improve their ratings...."

"Dr. Phil is a dumb ass. He panders to all that is sensationalistic. He has the empathy of a cancerous tumor and the intellect of a slug. Just an angry egotistical creep..."

I feel that Dr. Phil and his expert neurologist did untold damage to the viewers' perception of Asperger's Syndrome. Their impact on the public consciousness was devastating.

The next "reality show" to be discussed had a very positive impact on the viewers. However, Tyra Banks is not cloaked in the mantle of alleged expertise enjoyed by Dr. Phil.

# America's Next Top Model (2007)

On December 4, 2007 Tara Parker-Pope's article entitled "Asperger's Syndrome Gets a Very Public Face" appeared in the Health section of *The New York Times*. Parker-Pope described *America's Next Top Model* contestant, Heather Kuzmich, as a twenty-one-year-old art student from Indiana who has Asperger's Syndrome. What differentiates Heather from others with Asperger's is that for eleven weeks "her struggle to cope with her disability has played out on national television."

The author described Asperger's Syndrome as "a neurological disorder considered a form of autism." Furthermore, Parker-Pope explained that Heather is socially awkward, has trouble making eye contact, and "is sometimes the target of her roommates' jokes." In addition, Parker-Pope noted that people with Asperger's "often exhibit a single-minded fixation that can be both bizarre and brilliant."

Heather was one of thirteen young women selected by super-model Tyra Banks to compete for the position of American's Next Top Model on the popular reality show. Parker-Pope opined that "the addition of Heather Kuzmich to an otherwise superficial show has given millions of viewers an unusual and compelling glimpse into the little-understood world of Asperger's."

During the show, "cattiness and backbiting ensue." Heather is initially socially isolated. The girls whisper about her within earshot. At one point, the viewers see her crying to her mother over the phone. It is Bianca, an African-American college girl from Queens, who ridicules Heather the most. When Heather says that she wishes she could get the joke, Bianca says, "you, you're the joke." When Heather was interviewed, she played down the teasing, saying, "they didn't make fun of me that much."

Heather explained that she tried out for the show to test her limits. She wanted to know whether Asperger's would define her, or if she "was going to be able to work around it."

Although Heather's odd mannerisms separate her socially, these very traits make her appear "high fashion" in modeling sessions. She glances to the side because she cannot sustain eye contact, but she connects with the camera effectively.

Amazingly, Heather was voted viewer favorite eight weeks in a row. She was one of the most popular contestants in the show's four-and-a half -year history. Heather said that she was used to being ignored and had feared that her awkwardness would make the audience laugh at her. However, the opposite occurred.

She was among the last five contestants, but she was disqualified for flubbing lines in a commercial, and for getting lost on the way to see five fashion designers in Bejing. She was able to visit only one designer. During the scene in which she got lost on the way to see a fashion designer, Heather was in a panic. Doubtless, this vulnerability awakened even more viewer sympathy.

Despite not being a winner, Heather was the new face of Asperger's on both *Good Morning America* and *Access Hollywood*. She said that she planned to continue to model, and also to become a national spokeswoman for Asperger's Syndrome.

This highly positive and widely read article by Tara Parker-Pope undoubtedly had a most positive impact on the public consciousness. The value of Heather to the AS community would have been enhanced for any reader of the article who also viewed the show.

Despite my aversion to reality shows, I watched *America's Next Top Model* as soon as I was told about the contestant with Asperger's. I truly believe that Heather's inclusion was a blessing for the AS community. There are a few comments I would like to add.

First of all, it was mentioned on the show that Heather has Attention Deficit Disorder (ADD). Thus, it was not her Asperger's, but rather her ADD which was the cause of her flubbing her lines and getting lost in Bejing. Asperger's Syndrome alone does not explain the weaknesses she evinced during the show.

Secondly, a political issue arose during the show. The other girls, especially Bianca, resented that Heather was being "babied" by Tyra due to her disability. They also disapproved of the fact that Tyra Banks had insisted upon including a person with a disability. I found that quite surprising. Bianca, as an African American, should have understood that affirmative action can work in favor of a disabled person, as well as in favor of a person of color.

Finally, Heather never stooped to the level of the girls who ridiculed her, not even when they were choosing their beds and she was left without a bed. I believe that Heather's lack of spite and vindictiveness was a major reason that she won the hearts of so many viewers.

Thank God for this reality show! The question is whether it enjoyed as many viewers as Dr. Phil's episode on Asperger's Syndrome did. Even if Tyra Banks's show did not reach as many viewers, it had a very positive impact on the public consciousness because Heather emerged as beautiful, talented, and totally devoid of violence or malice. Heather Kuzmich's subsequent interviews most probably had an additional positive impact on the public consciousness with regard to Asperger's Syndrome.

Television series of a fictional nature enjoy popularity, especially those that concern the world of crime. With the exception of *Flashpoint*, I have chosen episodes from widely-viewed series, which automatically have the potential to impact on the public consciousness. Thus, no reviews are included

# Fictional Television Series

Series with Characters Designated As Having Asperger's Syndrome

#### Law and Order: Criminal Intent

Episode 14 from Season 2, entitled "Probability," dealt with an insurance fraud involving murders of homeless mentally ill persons. These homeless individuals were misrepresented as CEO's of major corporations, and their lives were insured for one million dollars each. Protagonist, Detective Robert Goren, initially consults with a fraud investigator by the name of Wally Stevens. Stevens is brilliant in his analysis of insurance fraud, but he is stiff and socially awkward.

Goren figures out that there is a conspiracy to murder the fifteen homeless people and notes that the murders occur in both spatially and temporally rigid patterns. Goren and his partner, Alex Eames, discover that Wally Stevens is divorced, and that his wife had taken out an order of protection against him. Wally would show up bearing flowers at the house of his former wife and her new husband. He would beg her to come back to him with the children.

The two detectives go to Stevens's house and confront him, informing him that they know his wife and children are gone. Moreover, Goren reveals that they know that Wally had killed the homeless people and had retained all the money from the life insurance policies. (Wally had also murdered his partner in the conspiracy because the partner had killed a homeless person outside the pre-determined pattern of fifteen victims.)

Goren shows Wally a page from an authoritative source on psychiatric disorders, in which Asperger's Syndrome is described. Wally cries out, "that's me! Why didn't somebody tell me?" The pathetic Wally Stevens is arrested, having found out, too late, what is wrong with him.

After viewing that episode, I was deeply disturbed and frightened because the portrayal of Wally Stevens made me think, "oh, God, what must the members of the public watching this think of people with Asperger's Syndrome?" If the episode impacted so negatively on me, given my background in psychology and my own issue with depression, it, clearly, must have impacted even more negatively on viewers in the general public.

# Law and Order: Special Victims Unit

Episode 136 from Season 6, entitled "Night," crossed over with Law and Order for the trial segment. It was widely publicized, owing to the presence of cast member Angela Lansbury portraying a wealthy socialite. The story begins with the investigation of serial rapes of undocumented alien women working as maids on night shifts. Due to their immigration status, they fear reporting the rapes.

It turns out that Gabriel, the son of Lansbury's character, is the serial rapist. Well before his guilt is established, the viewer sees Gabriel as a computer genius, who eats the same dinner at the same restaurant on the same night of the week. He barely acknowledges Detectives Stabler and Benson when they come to his apartment to request documentation.

I cried out, "oh God, not Asperger's Syndrome again!" But Asperger's Syndrome it was! Gabriel's attorney uses an insanity defense, but it fails because his own mother's testimony on the stand reveals that Gabriel did indeed know the difference between right and wrong. While out on bail, Gabriel is caught assaulting a woman in a subway station. His claim that the woman was "coming on" to him is of no avail. To clinch the guilty verdict, a former nanny of Gabriel's testifies that Gabriel, at the age of fourteen, had raped her while she was bathing him. It is revealed that the woman's daughter is actually Gabriel's child.

The extensive portrayal of Gabriel was made possible by the cross-over episodes, as well as by the outstanding acting by Alfred Molina. This portrayal rendered the depiction of Asperger's Syndrome a powerful tool to negatively impact on the public consciousness.

The next portrayal is of a character with AS was a regular in the subsequently-cancelled series. Although the initial impression of this character is very negative, the series plot allowed him to evolve and develop into a positive character.

# Boston Legal

It was with mortification that I viewed episode 12 of Season 2, entitled "Helping Hands." Attorney Jerry Espenson has been an associate with the fictional law firm for fifteen years. He moves stiffly, holding his hands rigidly at his sides. Thus, his colleagues nickname him "Hands." Jerry seeks to become Partner; however, Shirley Schmidt, portrayed by Candice Bergen, declares during a social hour in the conference room that Jerry is not partnership material. The attorneys, enjoying cake, are shocked when Jerry grabs Shirley and holds a cake knife to her throat. The distraught man threatens that if partner Alan Shore does not represent him, he will slit Shirley's throat.

Alan, portrayed by James Spader, is deeply compassionate to people with mental disorders. He promises to defend Jerry. Owing to thorough research, Alan learns that

Jerry has Asperger's Syndrome. Jerry, fearing that a trial will ruin his future, refuses to go to trial. Alan convinces Shirley to allow Jerry to come back to the firm, providing he go into counseling and take medication.

Jerry becomes a "regular" on the series. With the passage of time, his behavior becomes less and less bizarre. I watched one of the final episodes in which Jerry, now a Partner, advises a client. He also appears to be entering into a serious relationship with a lovely and supportive British colleague. It was a joy to me to see a person with Asperger's Syndrome become socialized after experiencing professional gratification. My only regret is that viewers who did not follow the series will remember the cake knife episode and associate this scene with Asperger's Syndrome. Nevertheless, Boston Legal's ongoing depiction of Jerry Espenson had the potential to impact very positively on the public consciousness.

In the next series to be discussed there is only one episode dealing with a character with Asperger's Syndrome.

### Flashpoint

This CBS summer series depicts a Strategic Response Unit (SRU) headed by Sgt. Gregory Parker who is a recovering alcoholic. He had lost custody of his son whom he has not seen for ten years. This aspect of Parker's life imbues him with special insight and compassion. Each episode tells the story of one of the crises the team handles. Although this is not a hit series, it was renewed for a second summer.

On July 16th, 2010, the episode was entitled "Unconditional Love." The character with Asperger's Syndrome, a teenage boy named Paul, who initially appears to be compassionate and heroic. Along with a baby, Paul is held hostage by a fugitive who has killed two police officers. Paul manages to save the baby to whom he shows great gentleness.

As the plot unfolds, we learn that Paul had planned to procure from the fugitive murderer weapons to kill red-haired girls. He goes to a skating rink and holds a young redheaded girl hostage. The team questions Paul's mother, who allows them to search Paul's room. The team finds in his room books and articles on serial killers. It is clear that Paul believes that he himself is a psychopath and a potential serial killer. Sgt. Parker questions Paul's mother, asking if he enjoys hurting people or if he is empathetic. The mother denies any cruelty on her son's part and claims that he is actually a victim of bullying at school. She further explains that Paul's red-haired sister has rejected him as her friend. Paul's mother had made him promise not to hurt his sister. Thus, Paul took her literally and instead chose to kill red-haired surrogates.

Parker then says that he believes Paul not to be a psychopath, but rather a person with a form of autism called Asperger's Syndrome. At the rink, Parker calms Paul down and assures him that he is not evil, but rather that he has an illness, which many others share. Paul releases the hostage, weeping with relief.

Despite the criminal act committed by the character with Asperger's Syndrome, the episode moved me deeply. I believe that it had the power to enlighten and to impact positively the public consciousness.

Although there were a few mixed reviews of the series, none even mentioned Asperger's Syndrome as portrayed in the above-described episode.

After seeing the disturbed but basically good young man portrayed in the *Flashpoint* episode, I was excited to start watching *Parenthood* to see how a child with Asperger's would be portrayed.

The final series to be discussed is a landmark in the history of family television shows. A child character has Asperger's Syndrome, and his extended family must come to terms with it.

# Parenthood (2010)

This new NBC series about the extended Braverman family has as its lead Craig T. Nelson, who starred in the original 1989 film, entitled *Parenthood*. Max, one of the child characters in the television series, has Asperger's Syndrome. Although many characters and relationships are explored, Max's diagnosis with AS has a powerful effect on his parents and on his sister. Very handsome, Max always dresses in a pirate outfit, which obviously sets him apart at his school. The boy is also said to throw tantrums and to bite. Max is expelled from school when he throws a fish tank to the floor because the gurgling sounds of the water are unbearable to him. His parents succeed in getting Max into a school for children with special needs.

One powerful scene occurs when Max and his family participate in a walk for autism. To Max's joy, the Braverman team wins. Max's parents have not told him of his diagnosis. The boy's psychiatrist explains that his parents will know when the right time comes to tell their son because Max will bring it up.

The reviews of the new series were mixed.

USA Today gave the new series a lukewarm review with only mention of a son with Asperger's Syndrome. The New York Times gave the series a good review, but made only a brief reference to the possibility that one son might have Asperger's Syndrome. The New York Post mentioned that Max's parents learn that their son has Asperger's Syndrome. Newsweek's review made no mention whatsoever of Asperger's Syndrome. New York Magazine, however, announced that Parenthood had been picked up for a second season. This indicates a wide viewership and bodes well for an ongoing impact on the public consciousness regarding Asperger's Syndrome.

It was the *Daily News* that proved the most informative. The review informed the reader that Jason Katims, Writer and Executive Producer of *Parenthood*, has a 13-year-old son with Asperger's. Katims was quoted as expressing the hope that the series would normalize Asperger's Syndrome for the viewers and remove from the condition the stigma so often associated with it. However, Katims did not want the series to

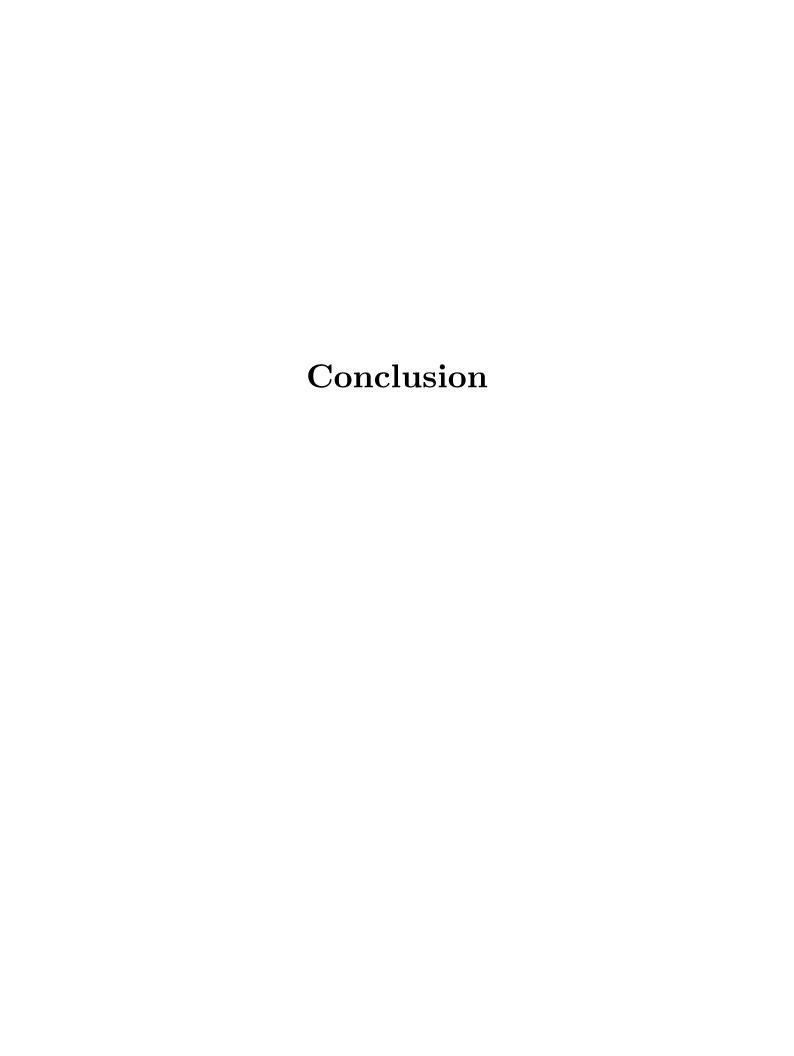
be too heavy. The Asperger's issue is placed in a larger context of the issues faced by many characters in the Braverman clan.

From what I have so far seen of *Parenthood*, Katims's purpose of inclusion of Max has been partially fulfilled. The Asperger's boy is a handsome, intelligent eight-year-old whose behavior is being addressed, by a social skills professional. The boy's tantrums are decreasing, and his behavior is generally improving.

My only problem with the handling of the Asperger's issue is that Max is being spoiled rotten. The family allows him to dictate what is on television and what food will be served. This is to reward him for not having tantrums. Of course, the rearing of Max must be viewed in the context of the contemporary tendency of parents to allow even non-disabled children a sense of entitlement that fails to consider the rights of others.

I hope that this series, which will continue in a second season, succeeds in destigmatizing Asperger's Syndrome. If AS is de-stigmatized, it will have a positive impact on the public consciousness – to be reflected in homes, schools, and workplaces.

The discussion of *Parenthood* concludes the section on Asperger's Syndrome in the media, The impact of writing this book on my own consciousness, as well as my views on core issues relating to Asperger's Syndrome, follow in this final section.



As an Aspergian explorer, I have reached the end of my odyssey. I have been irrevocably changed by the experience of intense researching, and then of writing this book.

I used to believe that we who have Asperger's Syndrome were separate and apart from "autistics." I no longer labor under this misconception. First of all, I have learned from my reading, as well as from personal experience, that people who began life as autistics may travel along the autistic spectrum to become more accomplished than many of us diagnosed with Asperger's. Every disability population is on a continuum, ranging from the most severe to the mildest form of that disability. The separation of Autism and Asperger's Syndrome into two diagnoses is a false dichotomy, which prevents more powerful social action and fundraising. I am now proud to call myself autistic.

The next question concerns the "cure debate." Certainly, any person suffering from depression, anxiety, or uncontrolled rage outbursts requires medical intervention. That, however, does not apply only to us on the autism spectrum, but rather to all persons with any type of challenge. We, who are on the autism spectrum, have uniquely admirable traits such as integrity, work ethic, ability to solve problems in unconventional ways, and, purity of motives.

Characters in film or television series, who appear to the general public to be clearly autistic, are generally portrayed as pure and devoid of evil intent. Characters with Asperger's, however, have been portrayed in recent years as capable of premeditated evil deeds. Therefore, it behooves those of us diagnosed with Asperger's Syndrome to bridge the divide and to join the autistic activists who seek respect for their differences, and also accommodation of their behavioral diversity.

In my opinion, the Asperger's Syndrome diagnosis has outlived its usefulness. Formerly, the diagnosis of autism meant a future without hope. The last few decades have introduced the public to remarkable individuals such as Temple Grandin. Thus, the public consciousness regarding autism has changed radically. Now it seems to me that melding autism and Asperger's into one "autistic spectrum" is an advantage to us with Asperger's Syndrome. In addition, the drafters of the forthcoming DSM-V appear to see no value in including Asperger's Syndrome as a diagnosis separate from autism.

For the purposes of political action, access to increased funding, and broadening of the public consciousness, the Asperger's/Autism divide must be eliminated. We are all on the same spectrum, and we should all be united in pride and in the quest for acknowledgement of our value and dignity. Unlike large populations such as Jews and African Americans, who can afford to be divided, the much smaller autistic population cannot afford the luxury of such divisiveness.

Having experienced discrimination based on my sexual orientation, color, religion, age, as well as on disability, I believe that we who have Asperger's Syndrome need to view our disability in the context of all persons who are treated as "outsiders." In that way, our public outreach will be more sensitive and compassionate. This will result in the public consciousness being impacted even more positively.

On May 11, 2010, at the annual GRASP benefit, I had the great pleasure of meeting Marc Sirkin, Chief Community Officer of Autism Speaks. The featured speaker was author John Elder Robison, who collaborates with both GRASP and Autism Speaks. This inspired me to believe that the two organizations could one day work together.

On September 7, 2010 I was invited by Marc to visit Autism Speaks at their new quarters, located at 1 East 33rd Street in New York City. There I met with him and the Head of Awareness, Dana Marnane. We had a wonderful meeting of the minds. I was given a packet of material on Autism Speaks. I suggested to Marc that in 2012 or 2013 Autism Speaks and GRASP could sponsor a joint event to express unity in our movement. Marc expressed interest in co-sponsoring such an event, and I said I would broach it to Michael John Carley.

I submitted my idea to Michael, who said that this would be possible only if Autism Speaks publicly changes its position regarding curing autism. Michael admitted that when discussing the relationship between our two organizations, on a one-on-one basis, it seems that Autism Speaks has changed its position. However, Michael would like to see the organization officially acknowledge that autism in itself requires no cure, but rather acceptance.

From reading the materials published by Autism Speaks, I saw a positive change. The emphasis on "cure" autism and the autism "epidemic" was effectively gone from the literature of 2009, as opposed to the 2007 literature. Adults with autism were receiving support and advocacy. Even senior citizens with autism were to receive services through Autism Speaks. An online resource "Autism in the Workplace" exists now. Fundraisers in the form of Walks and concerts raise money for research into treatment, and simultaneously raise public awareness. In 2009 there was the "First Strategic Plan for Autism Research." Autism Speaks consults with the Scientific Advisory Commission" to translate discoveries into effective research. Moreover, Autism Speaks is politically active, working with Congress to prevent discrimination in health insurance against people with autism. First founded in 2005, Autism Speaks has taken laudable action to help persons with autism and their families, and not simply to work towards a cure.

The Global and Regional Asperger Syndrome Partnership (GRASP), first founded in 2003, has taken ongoing action to help the Asperger's Syndrome community members and their families. Outreach has extended to Canada and Australia, as well as to Moscow. If groups were to be formed in these countries, GRASP would become truly international.

GRASP's bylaws require that the Executive Director, 100% of its Advisory Board, and 50% of its Board of Directors be diagnosed on the autism spectrum. In this respect GRASP is unique.

GRASP also funds support groups networks (23 in 2010) all over the United States. Further, there is a website which provides resources for diagnosis and treatment, articles on Asperger's Syndrome and updates on all developments regarding Asperger's Syndrome. Moreover, GRASP works with the New York City Public Schools to create and implement programs for their autistic students.

Finally, as its literature emphasizes, GRASP is willing to "engage with, rather than to demonize, ideological opposites." It is precisely this openness that has contributed to the increasing awareness of the needs and rights of the autism spectrum community.

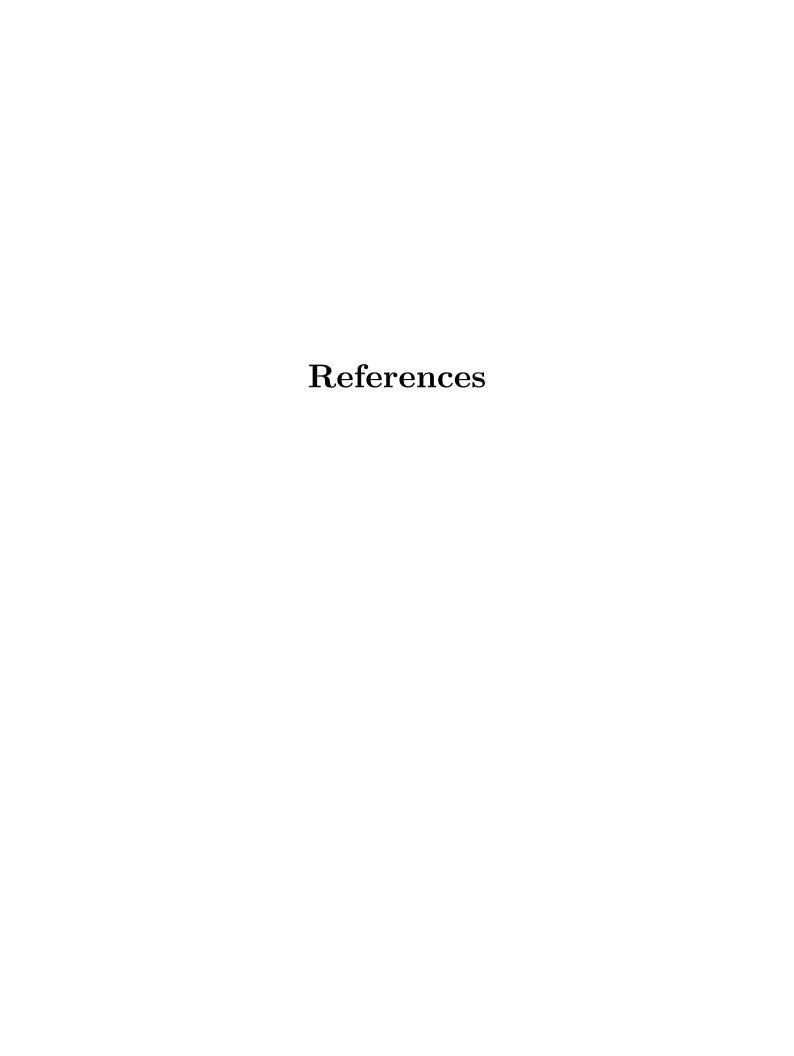
I have a dream:

That some day all the autism spectrum organizations will begin to organize together. That the autism community develop many special interest groups such as for writers, artists, scientists, technologists, sociologists, and mental health professionals

That an autistic spectrum organization become part of the academic community, as well as an influence in the creation of courses

That an autism spectrum center will be created, which will provide meeting spaces, counseling, and performance/lecture spaces

That is my dream.



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