

11/23/11 AUTISM SPECTRUM DISORDER FROM A FAMILY PERSPECTIVE

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INTRODUCTION

It is often said that when one meets one person with autism spectrum disorder (ASD), one has simply met one person with ASD. This disarmingly simple statement, wrought with meaning, conveys what is known not only from decades of clinical observation but also from the revelations of the many studies underway to understand the genetics and systems biology of ASD. Perhaps the same is true with families, and even within a family, where each member sees ASD through the prism of one person, and each family presents a unique challenge to the medical profession. Certainly the viewpoint of a parent raising a child is far different from that of a sibling, and each family constellation poses different challenges.

Many families are torn apart as parents struggle with one income, diminished career expectations, loss of intimacy, and social isolation (Smith et al., 2010). If asked for one word to describe their lives, the answer is invariably “stressful” (Barker et al., 2011), often followed by fears of “what happens when we are gone?” However, remarkably, while bravely accepting their situation and often finding extreme ways to adapt—moving to another state to find services, taking on part-time work to pay for early intervention, developing therapies on their own, and giving up vacations—the majority of family members show great resiliency and creativity in seeking ways to channel their talents and abilities to create better lives for their own as well as others with ASD.

The family perspective presented here is based on experiences over many years during which the authors have had the privilege of living with, meeting, and hearing from many individuals with ASD, their families, and numerous dedicated professionals, clinicians, and researchers. The purpose of this chapter is to offer medical practitioners new to the field a way to appreciate how profoundly ASD impacts the rhythms and patterns of family life.

THE PHYSICIAN AND THE FAMILY

The great range of behaviors and medical issues associated with ASD presents a challenge for the physician meeting with the family of a person with ASD for the first time. However,

as with every medical encounter, a physician, trained over many years in the practice of close clinical examination, chooses what information to privilege, a subtle aspect of the doctor's art, and the choice of frames into which to formulate a treatment plan.

Parents arrive at an examination ready to give detailed reports on eating behavior; seizures; gastrointestinal complaints; self-injurious and other-directed scratching, biting, and pinching; as well as obsessions with all manner of systems and structures. Self-injurious behavior is not uncommon: It includes hand biting, head banging, and face scratching as well as other unusual and incomprehensible behaviors, such as spinning, hand flapping, and bouncing. Parents are wondering what they might have done to bring this ASD on—something in their diet during pregnancy, or a stressful event, obstetric complication, or a family history of psychiatric illness—and they are hopeful that the physician has some answers.

Each individual case may appear to fit the broad definition of ASD in terms of deficits in social communication, and obsessive and repetitive behaviors, that the doctor has undoubtedly encountered in the medical literature or from the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (American Psychiatric Association, 2013). But parents entertain a hope that their individual experiences might offer important clues leading to a more physiological or neurological explanation for the obvious distress their child is feeling, and often with no means, other than “aggressive behavior,” to communicate where it is coming from. During the examination, the person with ASD may have little or no speech or may be highly talkative; he or she might be hyperkinetic—biting a wrist, flapping hands, spinning about, shrieking, and exhibiting various tics—or might just sit quietly staring off into middle space.

Fortunately, physicians are now in a position to give a more informed response to families in the examination room. This is because it is becoming accepted that ASD in most cases is caused by some event during development that may have affected the nervous, endocrine, or immune systems and their mutual interactions. As a result of these scientific advances, it is becoming more common for teams of medical professionals to make the first diagnosis of ASD and to set the agenda for integrated treatment and care.

Nevertheless, it is not a simple matter to connect the possibility that someone's synaptic machinery may be leaky, one explanation for ASD based on genetic findings, to the behavior of the person in the office who is darting to the cupboard to liberate bandages, surgical gloves, and syringes from their sterile wrappings or to another person sitting calmly, perhaps silently, observing with subtle sideways glances the events around him or her. For the physician, fashionable ideas about ASD from the neurocognitive sciences, such as the notion that these individuals lack “a theory of mind” or that they have strong local brain connectivity but weak global or “central” coherence, seem to lose relevance and serve up little in the way of wisdom that can be imparted to the anxious family member sitting opposite, or even to help structure the information the family brings. It would behoove a physician treating this population to become acquainted with the full range of treatments and remedies that a family might be considering, as well as to develop some sensitivity to the idea that ASD is not only about the brain (Herbert & Weintraub, 2013).

There was a time when it was common for doctors to assume that poor parenting caused ASD and to recommend that the parents see a psychiatrist. In that era, ASD, if viewed at all, was seen by experts as a psychiatric disorder, and the child was viewed as being lost in his or her own world, “choosing” isolation where, in reality, the child might be working hard to free him- or herself from it. These views still persist, having migrated to other forms of ostracism and insulting, sometimes abusive, treatment by those who have no comprehension of ASD, adding to the anxiety and stress on family members. Recently, more attention

is being paid to treating primary caregivers with “mindfulness” training and other forms of relaxation therapy. It is reported in a study from Vanderbilt University that mothers of individuals with neurodevelopmental disorders have significantly elevated levels of stress and clinical depression (Dykens, Fisher, Taylor, & Miodrag, 2014).

PERSONAL NARRATIVES

A good way for physicians to educate themselves about the impact of ASD on families is to read parent narratives (Greenfeld, 1970; Iversen, 2007; Parks, 1982), often written by professional writers (Savarese, 2007) or academics (Grinker, 2007). Although each describes unique and unforgettable scenes from everyday life, they share a nearly universal expression of love, commitment, and fear for the future beyond their own lives, reflecting the reality that ASD is a lifelong condition, not a lifespan-limiting disease. A theme running through many of these stories is the questioning of the assumptions behind the facile classification of persons with ASD as “low-functioning” and “high-functioning,” as if human beings are appliances that break down in the workplace and are not covered by a warranty. A careful reading of these books is probably the best introduction a young physician can have to the full range of devastation and adaptation experienced by a family.

Parents of children with ASD, already stressed emotionally and financially, are also beset by worries about the future of their child, a long adulthood and perhaps an old age without the emotional anchorage provided by their parents during their middle age. A valuable lesson to be shared with young parents is that some things do get better, especially after adolescence, as individuals with ASD develop an understanding of the world and achieve, in some cases, greater calmness and self-sufficiency in personal care and choice-making in daily life. Parents will be concerned about how to help their growing adults form friendships; safely learn about their sexuality and potential desire for intimacy; and deal with normative human experiences of loneliness, loss, and rejection.

It is important to realize that a person with ASD is not a closed book but, rather, capable of growth and change in many dimensions like the rest of us. Many adults with ASD, and not only those more recognizably labeled as “savants,” engage in the visual and musical arts, poetry, and writing—sometimes producing work of commercial value, but always with a sense of self-satisfaction and accomplishment. A few pioneers have gone on to college, with some earning degrees and some with aims to be advocates for others with ASD. One may see adults working today in supermarkets, warehouses, and local businesses; in libraries; and even in the computer and technology sectors, where their spatial and systems recognition abilities may hold special value.

We know a little about the internal world(s) of persons labeled autistic from the writings of Donna Williams (1992, 1994, 1996), Temple Grandin (1995), Tito Mukhopadhyay (2000), Naoki Higashida (2013), and others. Reading these four narratives should be enough to convince anyone that the human brain, fed by the senses, moved by the emotions, and experiencing muscular activity, can produce a staggering range of metaphors, artistic creations, and insights, even though it may be connected to a somewhat uncooperative body. Yet, many somehow see fit to attribute internal states to the outward appearances of behaviors and difficulties and to interpret severe problems in communication and social behaviors, or apparent misunderstanding, as a lack of interest in, or a paucity of emotional feeling for, others.

It is difficult to ignore the surface appearances and behavioral manifestations of ASD to get to the feeling, thinking person beneath, but confusing these outward signs and

impairments with definitive conclusions about affection, motivation, and capacity is a mistake. Inevitably, the result is to dehumanize the person with ASD, adding a veil of isolation to the person's already isolating difficulties.

One attempt to redefine ASD (Markram & Markram, 2010), by neuroscientists who are parents of an individual with ASD, posits that each person with ASD inhabits a unique, but almost unbearably intense, world in which each sensation or memory contributes to conscious thought with a weight, influence, or affinity outside what is considered normal. This causes one to wonder why anyone should be valued simply by how they fit into our everyday world of consumption, constant electronic bombardment, and frenetic movement when the novel combinations formed in isolated human minds, given means of expression, can give rise to delight, invention, and insight into what we all are or could be.

Increasingly, individuals with ASD are playing more active roles in planning their lives and defining their interests. As they become confident in creating new avenues for themselves, they begin to engage more in their own communities. These efforts are leading to an increase in activities for both young and old in sports (e.g., skiing, bowling, golf, and swimming), theater-going (including relaxed performance opportunities), hobbies (crafts, gardening, computers, yoga, and cooking), and interests in continuing education or participation in their religious or social communities.

A meaningful life need not be one of only working for a living, not always possible, or of achieving professional success but, rather, of having projects and involvement that offer opportunities for self-expression and participation in their communities.

THE CENTRAL IMPORTANCE OF COMMUNICATION

Opening any door to communication can change the life of the 30% of those with ASD who lack speech or have only minimally verbal means of expression. Throughout the 1960s, 1970s, and 1980s, there was very little expectation placed on these persons, and little in the way of hope—even the use of sign language was discouraged because it was thought to offer an easy way out of learning to speak. Today, we are learning much from the experiences of those who, either as children or as adults, have been taught new ways and methods to access communication through technologies such as computers, voice output devices, structured interfaces, and haptic anticipation. This may take years of hard work to accomplish, but it is of immense importance to family members who hope (and often awake from sleep with this dream fresh) to one day hear their silenced child or sibling express thoughts, feelings, and personality. New interests, educational opportunities, and relationships with others will evolve, opening up a world for that person and the lives of those around him or her.

Perhaps, with the means to express themselves for the first time, these individuals can explain where they feel pain to a doctor or describe aspects of their ASD such as noise sensitivities, or problems with certain clothing, or how their outward appearance may or may not match what they feel is going on inside them. Indeed, some clinicians (Robinson, 2011) conduct examinations in situations in which augmentative communications are encouraged and used as the patient types answers to questions posed by the doctor.

They may be treated for the first time in life as a “you” rather than spoken about in the third person, or over their heads, in their presence, as if they are not there; all the while, they may be listening and taking in the conversations, whether distortedly or clearly, even if their appearance may be distracted and nontypical. Achieving communication does not mean that the individual is no longer autistic by any means, but it does diminish the possibility that it is not ASD alone that defines him or her as a person. This view is strengthened by the

growing literature produced by writers with ASD, once classified as “low-functioning” and “retarded” (Biklen et al., 2005). Some professionals will acknowledge, if not publicly then privately, that the old assessments of intelligence are, or at least may be, mistaken; that testing methods are inadequate for those who poorly respond to tests or who cannot speak; and that the capacities and potentials of those with ASD may be often quite underestimated.

It is to be hoped that every school, clinic, doctor, or family involved in the life of an individual with ASD endeavor to solve this often central predicament for each and every child or adult in their lifetimes, whether through augmentative and alternative communication approaches or others. Technology holds the promise to deliver better means to enable communication and meet the challenge of unlocking the doors to the inner person. Although someday research will uncover the internal biological and systemic processes that interfere with the ability to communicate, and offer interventions or solutions at the source, there remain, in the meantime, lives that are being intensely lived, and the possibility of redirecting real-life trajectories sooner rather than later. By not acting, lives are being circumscribed and consigned to an isolation and loneliness few of us can imagine enduring, even if surrounded by the most caring people.

SIBLING PERSPECTIVES

Although parent narratives, and increasingly self-reports from individuals with ASD, appear regularly, the stories and experiences of siblings are less rarely seen. A notable exception (Greenfeld, 2009), by the brother of Noah, whose story and his family’s adaptive reaction were so movingly told by his father (Greenfeld, 1970) a generation ago, powerfully chronicles his and his brother’s transition to adulthood. Siblings who are close in age, such as Jonah and Karl, bring a very different perspective on ASD than a parent or an older sibling.

Young children, unlike parents, enter a world with no a priori expectation that the newborn or young child is anything but “normal.” They gradually come to realize that their sibling acts significantly different from themselves and their peers. A young sibling grows and experiences life with an autistic brother or sister, like any other family, first with all the joy and pleasure of playful growth and shared learning and then with love and affection, and the creation of private worlds. Gradually, awareness that something might be different, but not “wrong,” with their sibling appears, and they find themselves adapting inexorably, somewhat confusedly, and not always smoothly.

Young siblings today may be exposed earlier to what is happening as early diagnosis, specialized interventions, and altered household routines, such as the machinery of applied behavioral analysis, descend and family tensions increase (Orsmond & Seltzer, 2009). Autism spectrum disorder was once a term rarely heard, unlike today when it is often in the media and public mind, as well as firmly situated within a growing body, even enterprise, of professional approaches and research. At one point, children if asked about their own siblings were told to say “he is autistic,” and often heard back, “Oh, he is artistic, how nice!” This had to be disconcerting for a young person beginning to engage the social world outside of the home. Later, ASD came to be called “retarded” or “emotionally disturbed.” What was not appreciated in those times was that siblings may have lacked a framework to understand what those odd words meant and were unable to grasp fully the derogatory or sometimes sinister import of these labels, resulting in an uncomfortable, gnawing, realization that something is not right with the little person growing next to them.

The sibling may bring no notion of disability, judgments, prejudices, deficits, or any notions whatsoever of ASD or anything else; it is simply one’s own brother or sister—a

very real person both alike and different than oneself, endowed with all the intriguing, delightful, messy, irritating, and curious facts of personhood, even if he or she may well express him- or herself differently, as becomes more apparent over time. There can be a window of acceptance and relatedness, which one later learns is not necessarily the window the larger world has. Unencumbered by the responsibilities and worries of a parent, the child may find natural ways to relate to his or her sibling. In many cases, it is through activities enjoyed by both, whether through song, music, dancing, swimming, or other novel ways and games. This childhood oasis of ignorance can, in a sense, be a blessing. Strong childhood bonds are formed, even if they appear atypical compared to bonds with other peers.

But the outside world intrudes and forces upon a sibling what may be the most troubling aspect of all in growing up with ASD in the form of bullying, teasing, and taunting of a sibling because of the unusual sounds they make, things they say, or their preoccupations, generating an early stance of protectiveness. These episodes are not lost on the child with ASD, and they fall back on their brother or sister for comfort and understanding, even if it is not apparent. Adult siblings today report incidences of bullying or outright prejudice and intolerance from adults, sometimes on hospital wards, but most often in supermarkets, malls, and convenience stores. This is relatively new because ASD was once pretty invisible and the spectrum very much more narrowly defined; there were no special education mandates, and children with ASD were usually rarely seen or included in social gatherings, religious institutions, community life, and in family celebrations of weddings or religious holidays. Adults with ASD were a complete absence, perhaps hidden away or institutionalized, with visits from aged parents and siblings, portrayed with great impact in the movie "Rain Man" (Johnson & Levinson, 1988).

Despite all the positive changes that have occurred socially today, it would be helpful for parents (and professionals counseling them) to find good explanations and language, geared to a child's age and maturation, to help a "typically" developing sibling not only understand more about his or her brother or sister with ASD but also offer the sibling a way to explain to his or her friends, who may be curious or fearful about the child with ASD, what is going on. It is essential, however, to shape these explanations in terms that give the child an opportunity to relate (and help others relate) to his or her sibling rather than teaching the child to diminish the value of his or her sibling due to differences or difficulties. This can be a tall order in a society in which a person with ASD is more generally seen as alien, an outsider or less than fully human, even though that too is changing (Murray, 2008).

As one grows into adulthood, there can be a push-pull between the personal need to move beyond the family—entering into a more independent existence, going off to college, starting a career, or getting married—and the needs of the grownup sibling with ASD, which require ongoing strong family focus and involvement. Some siblings have spoken of feeling of guilt as they move on and out into life arenas their sibling did not enter. These are complicated emotions, involving feelings of leaving the parents to deal alone with issues at home but also the pain of separating from one so loved and so close. Some siblings feel the necessity of appraising future life mates, in part, in terms of how they relate to the sibling with ASD, knowing this relationship is both a valued part of life and one that the future mate would share in. As parents grow old and die, siblings often take on the role of supporting or navigating life planning for their maturing brother or sister with ASD, often putting stress on their own resources, both emotional and financial.

THE FAMILY AND THE SYSTEM

The physician treating a person with ASD will, of course, be well aware of the import of an ASD diagnosis, including the insurance and reimbursement practices in the community and state in which they practice. But what happens for the parents post diagnosis? What else in their lives demands attention beyond what the medical profession can give?

Many feel they are stepping off of a cliff, with few clear supports in place to help navigate the world with and for their child. First and foremost, they must figure out how to care for their child, often at home and with few extra resources to help in this care. They must learn about and engage in negotiations for appropriate therapies and interventions and determine how to pay for them after insurance coverage ends. The search for an appropriate school placement can be daunting, at times involving battles with administrators and teachers to secure a good educational setting. Extended family and social circles may or may not provide a welcoming atmosphere for the family with a child with ASD. Holiday celebrations and other family events (e.g., weddings, birthdays, and graduations) can be especially stressful.

Preparing for young adulthood, a time when educational benefits and supports end, requires extensive planning for employment training and exploring of options. Securing a residential placement or working out how to live at home well into middle age is a major concern. Arranging for ongoing supports and services for their family member often puts them into confrontational and contentious situations with social service systems and case workers who barely know the person with ASD. The tasks of financial planning and the securing of government benefits in those situations in which the autistic adult may not be self-supporting can be a full-time job unto itself. All the while parents must worry about who will care about and advocate for their young adult when they grow old or pass away. Siblings, if they exist, may or may not be able to provide continuity of support and emotional care as the parents have done, and themselves must carry on with life planning needs as they unfold, often with no professional or other network of support. Finally, all must think about the aging adult and what kinds of living, medical, and social supports should and will be in place when the immediate family may not be around.

FAMILIES RISING

These life challenges can be met with resiliency, compassion, and, often, an ethic and value placed on caring, empathy, and open-mindedness to the differences, vulnerabilities, and capacities of others with significant challenges, not just those with ASD. As in many aspects of life, sometimes seemingly difficult or nontypical experiences thrust in one's way prove to be instructive in surprisingly positive ways. This "silver lining" in no way diminishes the pain, uncertainty, and doubt experienced by the family, nor does it alleviate the sometimes difficult emotional and practical problems with which the family members grapple and that often cannot be shared with peers who have no such life experiences.

Parents, families, individuals with ASD, and the diverse networks they form can be a great inspiration and often driving forces in pushing the envelope for what is possible in the world of ASD, whether opening up new scientific directions, paving the way for new medical treatments and educational therapies, or in the social realm in terms of searching for new life options. Families often do not give up on the potentials that may unfold in a person's life, nor take as final or determinative "expert" pronouncements as to future capacities and growth in their own lives, and they often seek to drive progress in their communities or in

public advocacy. Of course, they do not necessarily see eye to eye on what form this progress should take because there is no one path applicable to all, and professionals should take heed and even embrace the open-mindedness of the families in their quest for a better life. A recent gripping account of human nature and variation situates ASD in the context of the disability movement and presents a comprehensive picture of what families face and how they are coping (Solomon, 2012).

SUMMARY

Over many years and many encounters, whether with families, those with ASD, or professionals, the authors have encountered multiple views of ASD as a concept, with some viewing it as a tragedy in need of cure and elimination; others perceiving ASD as a scientific, medical, or societal challenge; many seeing ASD as containing talents to be discovered and nurtured in the face of real and tough obstacles; some who value their ASD and have no wish to exchange it (or only parts of it) for another place in the world; those who see the “neurotypical world” as in need of change; and any number of variations in a wide arc of vantage points. As our understanding of ASD unfolds, this arc will no doubt shift and broaden with much to teach us all about our common human family.

KEY POINTS

- Parents often wonder what they might have done or how the environment might have caused ASD in their child. They are hopeful that the physician has some answers. As a result of recent scientific advances, it is becoming more common for teams of medical professionals to make the first diagnosis of ASD and to set the agenda for integrated treatment and care.
- A good way for physicians to educate themselves about the impact of ASD on families is to read parent accounts and personal narratives by individuals with ASD. These books are probably the best introduction a young physician can have to the full range of devastation and adaptation experienced by a family.
- The most pressing, central, and frustrating aspect of ASD is the difficulty of communicating. This has a profound effect on the family, especially for siblings, who construct a social consciousness for themselves that might be without parallel among their peers.
- Parents need to determine appropriate therapies and interventions, supports and services, and educational settings, as well as meet financial challenges related to residential planning for adulthood and prepare for a time when the immediate family may not be around.
- Families confronting ASD show great resiliency in adapting to the realities they face in providing a home environment, seeking schooling, employment, recreation, and medical care while at the same time trying to look after their own emotional and marital health. Many still manage to find time and energy to advocate for others and share their experiences.

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REFERENCES

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Barker, E. T., Hartley, S. L., Seltzer, M. M., Floyd, F. J., Greenberg, J. S., & Orsmond, G. I. (2011). Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology*, 47(2), 551–561.
- Biklen, D. P., Attfield, R., Bissonnette, L., Blackman, L., Frugone, A., Mukhopadhyay, T. R., . . . Burke, J. (2005). *Autism and the myth of the person alone*. New York, NY: New York University Press.
- Dykens, E. M., Fisher, M. H., Taylor, J. L., & Miodrag, N. (2014). Reducing distress in mothers of children with autism and other disabilities: A randomized trial. *Pediatrics*, 134, 2.
- Grandin, T. (1995). *Thinking in pictures: And other reports from my life with autism*. New York, NY: Doubleday.
- Greenfeld, J. (1970). *A child called Noah: A family journey*. New York, NY: Harcourt Brace Jovanovich.
- Greenfeld, T. J. (2009). *Boy alone: A brother's memoir*. New York, NY: HarperCollins.
- Grinker, R. (2007). *Unstrange minds: Remapping the world of autism*. New York, NY: Basic Books.
- Herbert, M., & Weintraub, K. (2013). *The autism revolution: Whole-body strategies for making life all it can be*. New York, NY: Ballantine.
- Higashida, N. (2013). *The reason I jump: The inner voice of a thirteen-year-old boy with autism* (K. A. Yoshida & D. Mitchell, Trans.). New York, NY: Random House.
- Iversen, P. (2007). *Strange son: Two mothers, two sons, and the quest to unlock the hidden world of autism*. New York, NY: Riverhead Books.
- Johnson, M. (Producer) & Levinson, B. (Director). (1988.) *Rain man* [Motion Picture]. Beverly Hills, CA: United Artists.
- Markram, K., & Markram, H. (2010). The intense world theory—A unifying theory of the neurobiology of autism. *Frontiers in Human Neuroscience*, 4(224), 1–29.
- Mukhopadhyay, T. R. (2000). *Beyond the silence: My life, the world and Autism*. London, England: National Autistic Society.
- Murray, S. (2008). *Representing autism: Culture, narrative, fascination*. Liverpool, England: Liverpool University Press.
- Orsmond, G. I., & Seltzer, M. M. (2009). Adolescent siblings of individuals with an autism spectrum disorder: Testing a diathesis-stress model of sibling well-being. *Journal of Autism and Developmental Disorders*, 39(7), 1053–1065.
- Parks, C. C. (1982). *The siege: A family's journey into the world of an autistic child*. Boston, MA: Little, Brown.
- Robinson, R. G. (2011). *Autism solutions: How to create a healthy and meaningful life for your child*. Ontario, Quebec, Canada: Harlequin.
- Savarese, R. J. (2007). *Reasonable people: A memoir of autism & adoption*. New York, NY: Other Press.
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40(2), 167–178.
- Solomon, A. (2012). *Far from the tree*. New York, NY: Scribner.
- Williams, D. (1992). *Nobody nowhere*. New York, NY: Times Books.
- Williams, D. (1994). *Somebody somewhere: Breaking free from the world of autism*. New York, NY: Three Rivers Press.
- Williams, D. (1996). *Autism: An inside-out approach*. London, England: Kingsley.