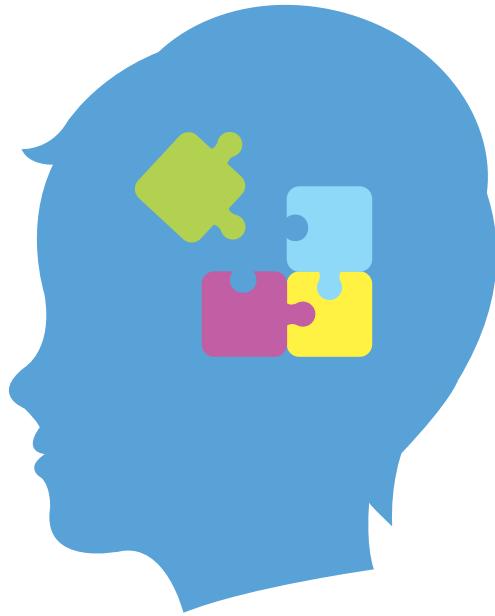




At the End of the Rainbow

Living with high-functioning
Autism Spectrum Disorder



Six-year-old Libby S.* charms every adult she meets. She's cheerful, affectionate, and delights them with her precocious vocabulary and clever observations.

That's why her grandparents, aunts, and even her therapist refuse to believe that she is autistic. While one might assume that people with milder autism should have it easier, this distinctive group faces a unique set of challenges and complications.

What is Autism Spectrum Disorder (ASD)?

Note: A full explanation of this condition is beyond the scope of this article. Symptoms are described only to increase the reader's understanding. Individual guidance should be sought from qualified professionals.

An oft-repeated adage goes, "If you've met one person with autism, you've met one person with autism." ASD can be hard to describe and recognize because its presentation can vary widely between each individual.

Libby's grandparents may have a hard time relating to her diagnosis because in the past, autism was believed to be a rare and severe disorder. However, the core symptoms of social impairment and restricted, repetitive behaviors exist along a

wide continuum. While this spectrum does include individuals who are completely withdrawn, it also includes many whose differences are more subtle but still cause functional difficulties.

So while Libby's language is above average and she can easily captivate a willing adult audience, she has a hard time making friends in school because she doesn't know how to join conversations or relate to what others are interested in. And while she doesn't sit in a corner banging her head or flapping her hands, her "restricted, repetitive behavior" includes a need for predictability that leads to intense meltdowns when things don't go the way she expects.

Social and communication deficits can include difficulties or failures in initiating or responding to communication, sharing interests or emotions, following back-and-forth conversation patterns, and nonverbal communication. While people with ASD typically feel more comfortable by themselves, that doesn't always mean that they don't *want* to connect — they just may not be able to.

"Mendy* constantly asks me why he has no friends," bemoans one ASD mom. "He wants to play with the other kids, but stands quietly on the side, not facing them, and they don't think he's interested. When someone reaches out, his response pushes them away so they don't try again. He does want to socialize; there's just too much he needs to learn!"

The other major feature of ASD is "restricted, repetitive patterns of behavior, interests or activities." This may

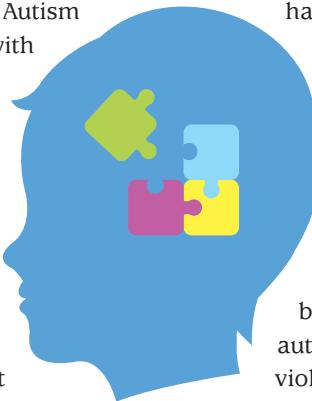
When a child's symptoms are mild, the diagnosis is likely to be a long journey with several wrong turns.

include repetitive motor movements or "stimming," intense interest in a particular subject, and/or a strong need for sameness, expressed by rigid routines and difficulty adapting to changes in the schedule or environment. This category also includes the sensory processing issues so commonly seen in children with ASD.

The autistic mind that seems to work so differently than others is different in positive ways, too. A mind that can focus intensely on a narrow field, unfettered by social concerns, has a distinct advantage over the average mind. Autism often comes packaged with a remarkable memory and pattern-based thinking. It is not a coincidence that many of the biggest innovators in science, technology and mathematics either have autism or probably would have been diagnosed with it if the knowledge had been available in their time.

A Day in the Life

Parents of high-functioning children sometimes feel guilty looking for understanding and help when others seem to have it much worse. There are no organizations offering respite to give families a break — if you're "high functioning" then how badly can you need it? — but ASD at any level is no



picnic.

Aliza's "sensory hyperresponsiveness" means she can't dress up or wear a *sheitel*, making it hard to participate in certain events and venues. She completely shuts down when faced with overwhelming noise, lights or other sensations.

Mendy's "need for sameness" means his family can rarely travel together. Families with autistic members tend to avoid outings and events because *something* is likely to trigger a meltdown.

When Ruchi's other children have guests over, they need to accommodate their ASD sibling, which can get annoying. Siblings of kids with ASD need to adjust to being different, and sometimes can't help feeling embarrassed by their autistic sibling's inappropriate behavior. Even high-functioning autistic children may act out violently, inadvertently hurting siblings and disrupting family life.

Parents' lives can become consumed with coordinating their child's care. Programs for high-functioning children are scarce, so parents need to find (and often fund) resources independently. This may entail shuttling them to different locations for occupational therapy, social skills training, counseling, psychiatric help, medical doctors (people with ASD are more prone to digestive and other problems), etc. Attempts to juggle all this with the needs of other family members is a recipe for tension and guilt. It can also impair Mom's social life and ability to contribute financially.

What happened to Asperger's?

In its 2013 revision, the DSM, which defines diagnoses of mental and behavioral conditions, replaced separate categories including Asperger Syndrome, PDD-NOS, and Autism with a newly defined Autism Spectrum Disorder.

The differences between the previous categories had always been vague, and were often subjective. A person could get a different diagnosis depending upon which doctor he saw or even depending on his socioeconomic status. This led to uneven distribution of services, with more help being granted to those deemed lower functioning when in fact others may have needed it just as much. Furthermore, sorting ASD into separate categories was not practically meaningful because one's level of functioning can change over the course of life or in different settings.

The change created confusion among laypeople, many of whom were startled by the idea that their high-functioning loved ones now bore the same diagnosis as a group previously stigmatized and marginalized. But the hope is that improving our understanding of the entire autism spectrum will lead to greater acceptance and integration for all.

Getting Diagnosed

When a child's symptoms are mild, the diagnosis is likely to be a long journey with several wrong turns.

The first noticeable signs may not be ones that are easily identified with autism. A parent who first notices her child's anxiety may look for help from ordinary parenting books or child therapists. A preschool teacher who notices that the otherwise bright child doesn't participate in playtime may think she's just shy. The grade-school child who doesn't understand appropriate speech and timing is perceived as "chutzpadig."

Even as more pieces of the puzzle begin to emerge, it's easy to blame something else for each thing because it seems so unreal that your precious child — who's so "normal" — might have a serious condition that will affect his whole life. With high-functioning ASD, you can get away with that for a while because there is nothing glaring that interferes with denial.

Even among professionals, understanding of mild ASD is still emerging. A parent might bring her concerns to the pediatrician only to be told that she's worrying too much because her child is meeting all the major milestones. She has a niggling feeling that something isn't right, but grabs onto this reassurance to keep things normal a little longer.

Girls with autism may be especially likely to be misdiagnosed. Their social difficulties may appear more like shyness or anxiety. Their restricted interests are more likely to take socially acceptable forms — for example, an obsession with dolls could easily be mistaken for a normal interest.

When a child appears similar to others, it's tempting to pretend he is actually just like everyone else. But because children

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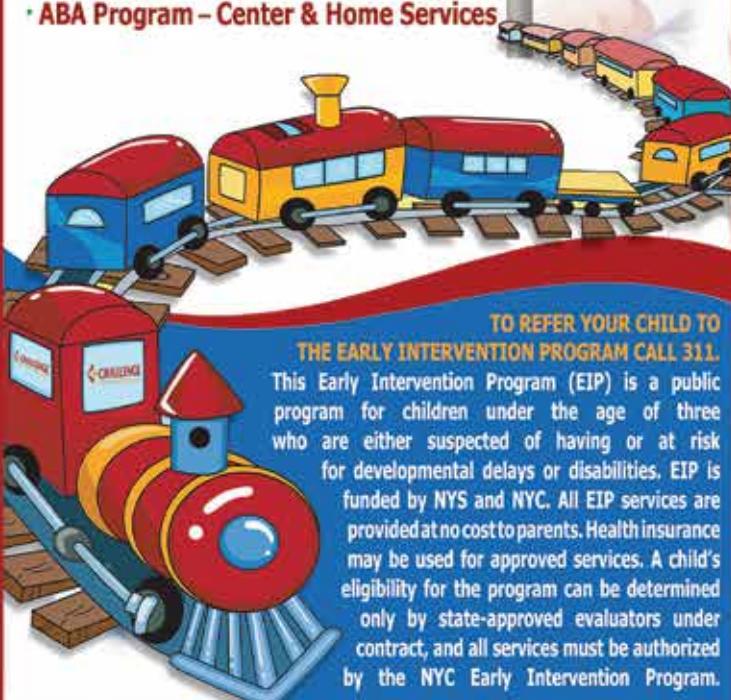
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Teachers, especially of young children, are invaluable partners when it comes to early identification and treatment of ASD. School is more socially and cognitively demanding than home, so differences can be more noticeable. Principals should help ensure that staff are educated and alert to the subtle signs of ASD.

with autism learn and think differently, it's vital to recognize and address their special needs.

Mordechai Meisels, M.S.Ed, BCBA, who has worked extensively with this population, explains that regular parenting, teaching and counseling techniques may be ineffective or insufficient for a child with ASD. The longer one waits for a diagnosis, the more damage is done while both parent and child are frustrated by everything that doesn't work. In contrast, accessing appropriate services earlier in life leads to better outcomes.

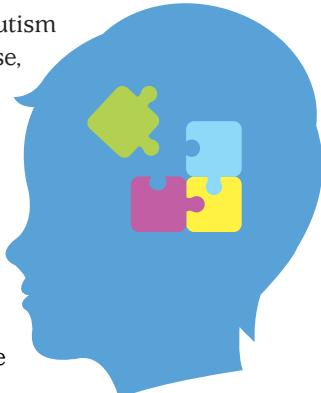
Seeking a developmental or neuropsychological evaluation may seem frightening, and the diagnosis can feel devastating, but it is an important step in a child's growth. A diagnosis can help you understand what you're dealing with and open the door to helpful therapies and services. If you have a feeling something might be going on, it's worth investigating rather than waiting.

Who knows?

Because people with mild autism outwardly appear like anyone else, they have the option of hiding their diagnosis. Whether or not to share it is a personal decision that is not easy to make.

Sharing personal struggles makes us feel vulnerable. You may worry about negative perceptions or stereotypes. Will people look at you differently if they hear you have autism?

Miriam wishes she could reach out for support but worries about Libby's future, including *shiduchim*. "I have such high hopes for her," she says. "Between her



intelligence and therapies, it's possible she will be fully functional as an adult. Will it come back to haunt her if people know that when she was a young child she had autism?"

On the other hand, people can be even more judgmental when they don't know about the problem. If you look typical, you are expected to act typical. Mendy's father can't bring him to shul because the other men get angry at both of them when he makes noises or moves around in unexpected ways.

"When my neighbor brings his kid with Down syndrome, they are so friendly and welcoming. You can see he has an issue, so nobody says anything when he acts up." By keeping ASD private, are we depriving ourselves and our children of the same understanding?

Nearly a year after her son was diagnosed, Ruchi decided she was ready to stop carrying the burden alone. She also hoped that her openness could help destigmatize autism. Thankfully, the revelation went well: People were compassionate, accepting and willing to learn how they could help make life easier for her son. Ruchi had felt so alone, pretending things were fine while struggling privately, and opening up about her son's ASD enabled her to connect again. Parents of children with ASD and other disabilities thanked her, saying that her openness gave them strength and hope.

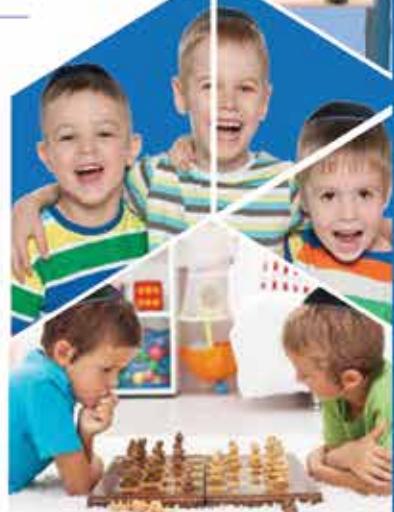
Ruchi feels that her community's positive response is a reflection of her own attitude. "We don't project any shame or discomfort, so they don't view it that way." But she is learning to balance sharing with her family's need for privacy, especially as her son gets older and may be more sensitive about his personal details.

School Blues

Finding an appropriate educational setting is one of the greatest challenges of high-functioning ASD. This problem is

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Children with autism fare best with educators who are trained in specialized methods that work for them.

especially pronounced within the *frum* community, as options and resources have expanded in the public schools while we still lack any specialized programs for high-functioning autistic children.

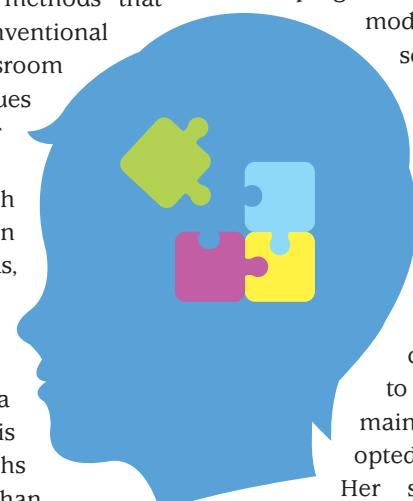
Children with mild autism are often not only intelligent, but exceptionally so. They need to be with people who can relate to them, and they need intellectual stimulation. Existing special-education schools designed for children with more severe disabilities are not appropriate for these children.

Meanwhile, the mainstream schools are also unequipped to meet these children's needs. Children with autism fare best with educators who are trained in specialized methods that work for them. Conventional teaching and classroom management techniques are often ineffective or counterproductive.

While children with ASD may be gifted in certain academic areas, challenges in skills such as inferencing and writing are common. They are best served by a complete program that is tailored to their strengths and weaknesses, rather than making the child adapt to a program intended for children who think and learn differently.

In addition, the larger class sizes and busy environment of a typical school are a poor match for children with ASD. They may be overwhelmed by the sensory onslaught and stressed by the need to interact with many people at once. For some children with ASD, the demands of a mainstream school environment trigger crippling anxiety.

Parents often have to think out of the box and leave their comfort zone to do what's best for their child in this situation. Aliza, whose fourth-grader also has ASD, chose to place him in a public school where he benefited from



better testing accommodations, easier access to services such as social skills counseling, and a more structured management style. They also found that he was more comfortable among people who were used to accepting diversity in various forms, while in the yeshivah his differences stood out more.

Later, he transferred to a Nest program, a highly successful model within the public school system that is designed specifically for high-functioning ASD students. He is thriving with the very specialized support he receives there.

When Ruchi's child became unable to function in his mainstream school, she opted for homeschooling. Her son is now taught by a team of teachers and therapists sent by a therapy center, which is funded through a combination of health insurance, Department of Education programs and a scholarship. It took considerable time and effort to figure out the best approach for his needs, but with this specialized team focusing on him individually, they have been able to achieve tremendous progress.

Those who are still struggling to succeed in mainstream schools need to find other ways to support their children's special needs. Mr. Meisels founded Encore Support Services in New York City to maximize the effectiveness of service provision for these children. His approach involves advocating for

increased specialized services, training and supporting therapists to provide these services, and providing supervision within the schools to ensure that the programs are running optimally.

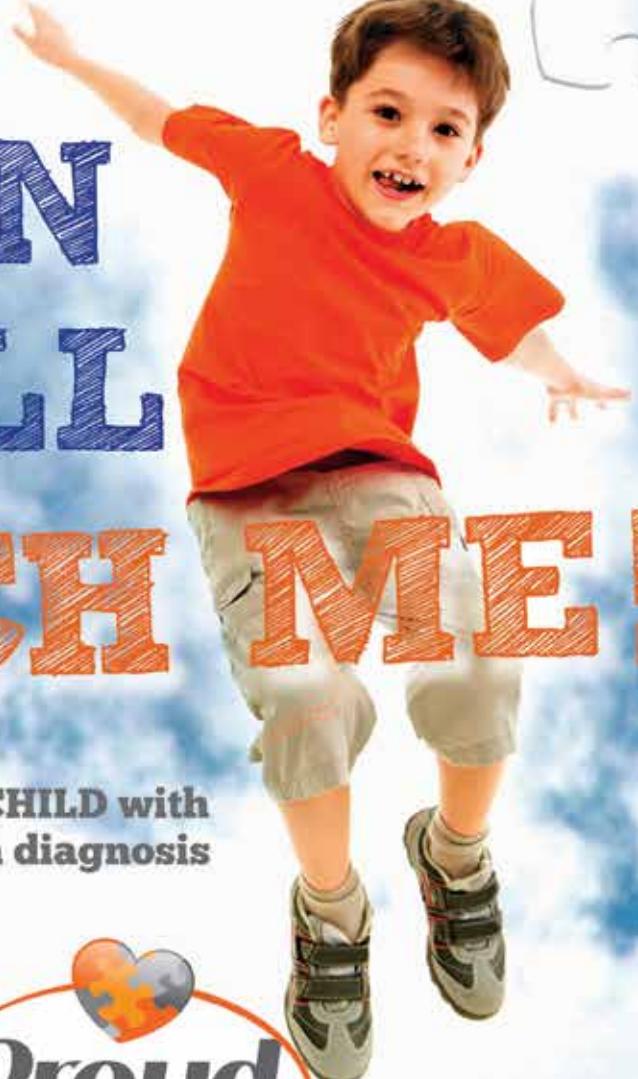
This is the first year that this program is widely available, but it promises to be a major improvement for mainstreamed students with special needs.

Living Together

After decades of confusion, despair and judgment, the world's understanding of autism finally seems to be maturing. In the mid-20th century, people with autism were viewed as abnormal and often institutionalized, to their great detriment. In ensuing years, various forms of treatment focused on trying to make autistic people as unobtrusive and similar to typical people as possible, often employing invasive methods such as shock therapy, strong medications and harsh punishments. Later, the quest for cures and prevention grew to encompass biomedicine and genetics research.

As generations of highly-functioning individuals with autism grow up and find their voices, the tide may be turning towards greater understanding and acceptance of what makes people with autism tick. While there is certainly a role for intensive therapies to help ameliorate the inherently challenging aspects of ASD, the emerging voice of autism seems to be saying loudly and clearly that what it needs most of all is a world that respects and accommodates those who think differently.

Two years after her son's diagnosis, Ruchi reflects: "The day we stopped



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If friends, employers and colleagues can learn to embrace autistic people without insisting on social mores, we will all benefit from the ability to work together.

making our child do things that weren't right for him, even if that's what all the other kids were doing, was the day we all started to thrive."

Pushing people with ASD to do more "normal" things tends to backfire — acting "normal" doesn't change their inherent differences, and instead creates a great deal of pressure and anxiety that makes it even harder for them to function. There is evidence that the most successful adults with autism are those whose parents accepted who they were, respected their special interests and accommodated their needs. Being happy and at peace with themselves enables people with autism to function at their best — much as it would for anyone else.

Instead of simply trying to silence the autistic child's challenging behaviors, therapists are now asking why — and our increased understanding of autism helps answer that question more helpfully. By understanding the reasons for a child's behavior, we can help him function better by providing what he needs, whether it is a quieter environment, advance preparation for changes, or the words to express his feelings.

ABA, the therapy of choice for autism, is no longer just about modifying the child's behavior through rewards and punishments — it is now just as much about modifying the environment to enable the child to function optimally.

If a person with autism has a hard

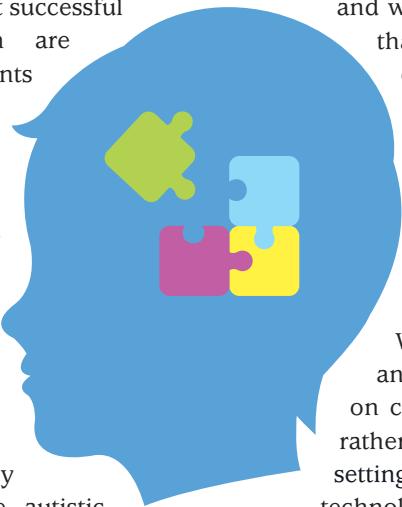
time fitting into society, the problem may lie more with the society than the autistic individual. According to current estimates, autistic people constitute the world's largest minority group. When a person has a physical disability, we build a ramp — we don't wait for the disability to be "fixed." Likewise, we should be willing to welcome autistic people into our communities, schools and workplaces without insisting that they first conform to our expectations. We should be receptive to alternative modes of communication and aim to make shared spaces more sensory-friendly.

The 21st century is ripe for this type of change.

With a lot of communication and work now taking place on computers and smartphones rather than face-to-face social settings (largely thanks to the technological innovations of geeky autistic geniuses), people with autism can interact with others more than ever before. If friends, employers and colleagues can learn to embrace autistic people without insisting on social mores, we will all benefit from the ability to work together.

While teaching children with autism to improve their communication and social skills remains a top priority, it is equally important for neurotypicals to meet them where they are so they can achieve their potential.

"The one thing I wish I'd known," relates one mother who spent years frantically searching for a miracle cure for her son who remained autistic, "was how well he'd turn out after all." ●



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