



# We're All <sup>in</sup> the Family

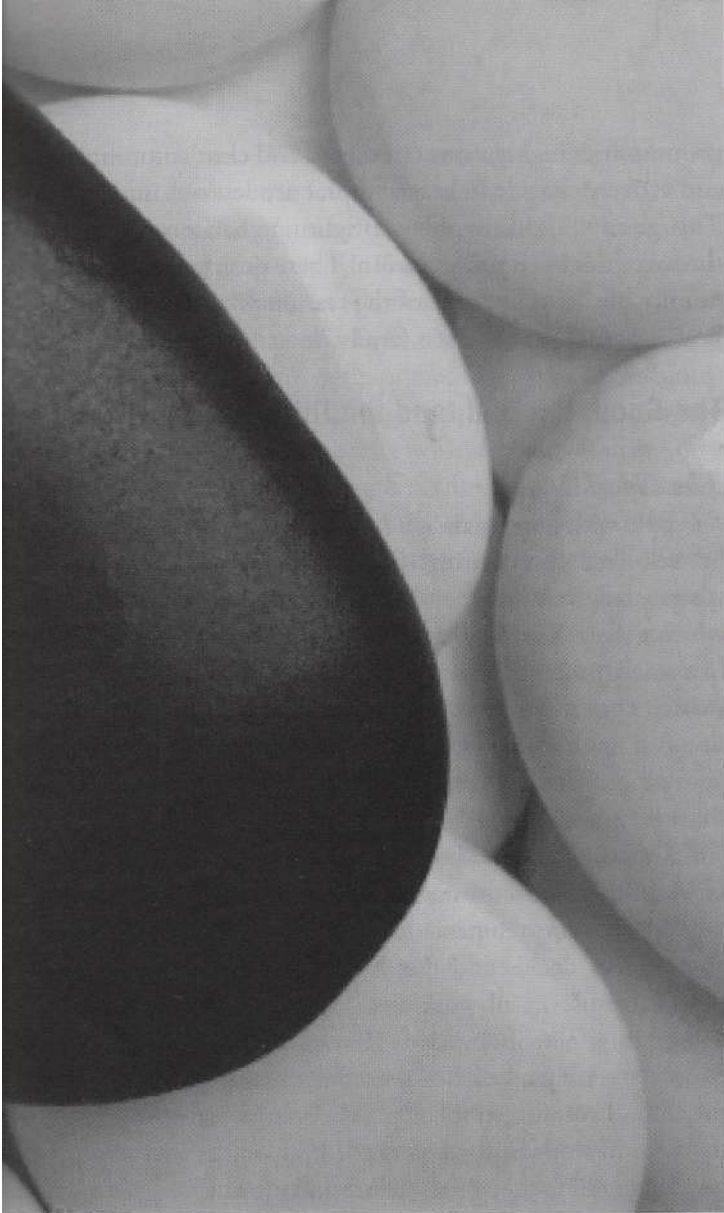
By: Elizabeth Barr

It is almost certain that you will have an opportunity to meet, work with, and even love someone with ASD (an Autism Spectrum Disorder), whether they are born/adopted into your blood family or move in to your chosen community family. This broad definition includes everything from the classic autism that most people associate with the condition, at one end of the spectrum, to high functioning autism (HFA) or Asperger's Syndrome, at the other end. The explosive growth in numbers of ASD children being born has been called both a sad epidemic and the next positive step in human evolution, as the brain structure of people with ASD is different in very basic ways. Though no one is quite sure why so many more of these people are coming into the world, they are certainly here. The more that "typical" people understand how ASD people experience the world, the better our entire human family can learn to live well together.

I have been reflecting on my own life, and realizing how well I fit the pattern that is now called Asperger's Syndrome. Frankly, it's a relief to have a name for it, and myself. Screaming tantrums in childhood? You bet. Weird style of walking? Yes, and I still remember clearly the day a classmate said, "Why do you walk so funny?" Terrible handwriting—oh yes! And, finally, social misfit? Social failure would be more accurate,

and that has remained true throughout my adult life. When I recently got back in touch with a good friend from middle school, I asked, "How do you remember me, from school?" and his reply was sadly affirming of my new understanding. "Well, we all thought you were kind of strange and you didn't really have any friends, but you were smart, so we let you hang around with us." I was grateful then for the tolerance, and grateful now for the validation that I was not the only person who thought I was different.

Seeking relief or definition, I've tried to lay claim to many other conditions, naming myself as alcoholic and bipolar and various other things in life. But if they were true, then presumably others would recognize it and the interventions that work for those would be helpful to me. Instead, trained professionals tell me I'm "okay" and nothing I do helps with the core issue—not really understanding how people work. I'm the constant tourist, the cultural anthropologist trying to blend in with the natives through careful observation and mimicry. And despite a lifetime of practice, my real understanding never gets better, although I do think I'm getting better at the copying. In a course of events that I now know is common, during my efforts to help my child manage the world better, I've become more informed about autism and Asperger's, and realize I've



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time I don't even mind, though it does sometimes feel lonely). But online, I get positive comments about what a fantastic communicator I am! How strange, that both sides of the same thing could be true. In any event, I'm glad to be getting more involved in a place where it seems like I'll be able to do well.

But I have found at least one "real life" place that welcomes pretty much everyone, and that was "on the farm" in a rural commune (not The Farm). It has been the only place I've lived that felt like Home to me in my adult life, has been the only place I've made friends I've stayed in touch with at all, and is the only kind of place I'd move to again. But as great as it was for me, I know there were things about me that were hard for other people there...to them, I apologize, but I just didn't know who I was then. Now that I do, things are much better in my life, and would be for all of us, if we lived together again. I'm grateful for your compassion and patience during our time together, especially since you didn't know the right things you needed to understand about me, either! We were all making it up together and did the best we could.

### **Born In or Moved In**

Autism spectrum differences tend to run in families and are more commonly diagnosed in boys than in girls. The prevalence is up to 1 in 166 births, and some say as high as 1 in 150 births. Perhaps you know a family who says "All our boys are like that," or "His dad was the same way," or other phrases that imply there may be a genetic cause. In my own family, this is certainly the case, and was the main reason it took us so long to actively seek services that could be helpful to Ethan. All our guys have shown at least some of the classic signs of Asperger's Syndrome, so in our minds, that's just how boys are. Fortunately, Ethan's experience of school and life is better than it was for my brothers, because we are helping him get the support and interventions that he needs. You may have a brother or dad who could meet diagnostic criteria for Asperger's...or perhaps you even recognize yourself!

In your chosen family, community life (especially rural) suits many Aspies very well, and they are likely to find their way to you eventually. It is usually easy to find work that is hands-on and does not require writing or paperwork in general—both of these areas are excruciatingly difficult for many people with Asperger's. Flexible work times and varied schedules provide the time they need to decompress and be alone, without seeming anti-social. If your group wants a website or other online presence, then your Aspie may be a great choice for that role, too, since the online world feels very comfortable and understandable. Long hours of unsociable alone time, while still engaged in productive work, is a win/win combination! Many

already been down the road he's on. His life feels so familiar to me, especially as compared to my older "typical" child, who has many friends and skips joyfully along through the intricacies of high school relationships and general drama. She seems like the different species, to us!

Most recently, I have been making drastic changes in my own life, based on my new awareness and understanding of myself. I've quit my teaching job, which required long hours of sociable behavior with many people and left me an emotional wreck at the end of each day. I decided to try something completely different that I thought might be a better fit and now I am getting paid to chat online, and it really does suit me much better! I have quit several groups I was in, and am spending more time at home, doing less for fewer people, while I instead use my time to develop my online life and world.

I've found that online is a place that feels very right for me, and the observer side of me breathes a sigh of relief as I feel comfortable and relaxed for the first time in many years. I'm 20 years behind, I know, so there is a lot to learn from scratch. The most fascinating part is about communication. For my whole life, I've been told that I'm bad at communicating and I readily admit it has been true—my lack of skill in talking to people has resulted in a very solitary existence (which most of the

## How to Get Along with Your Asperger's Neighbor

### What To Do

- Plan for change. Even just a few minutes' advance notice about a change in plan can be very important to help your Aspie neighbor cope better.
- Allow for think time. Expect them to need time to think about something first, before they are ready to respond.
- Encourage healthy eating. (This is good for you, too!)
- Go outside. Invite your neighbor on a walk or include them in any kind of community project that encourages working together.
- Be honest. No, they won't "get the hint" if you are trying to be polite, so just go ahead and say what needs to be said. You can bet they will, too!
- Include them. Small group situations are best. Small groups with structure, or based on a common interest or activity, are even better.

### What To Avoid

- Avoid surprises, especially if they create a disruption in the routine. Think of the routine as your neighbor's medication.
- Avoid rushing into any conversation, especially if it might be sensitive for any reason. Being rushed feels like being trapped, and your neighbor is likely to respond defensively.
- Avoid foods that are known allergens for ASD people, such as wheat, dairy, sugar, and preservatives/dyes. There are many ways to express an allergy, not just a runny nose. Emotional outbursts can be greatly reduced by avoiding these foods.
- Avoid or reduce isolation, lethargy, and apathy by actively reminding your neighbor to get up and get out.
- Avoid your own fear of expressing emotions. The Aspies are overly expressive, perhaps, but at least you'll know what's going on, plainly.
- Avoid exclusion. They won't learn how to be sociable unless they practice, and "typicals" won't learn how to be accepting unless they practice, too.

communities highly value structured and clear communication, and actively provide lessons and practice sessions in these skills. This gives the socially inept a fighting chance at figuring out the mysteries of communication. These positive aspects of community life are only some of the reasons why you will probably find Aspies in your chosen family, too.

## The Good, the Bad, and the Different

### *The Good*

People with Asperger's Syndrome have good qualities and can be well-liked contributing members of your community. They are generally very smart and enjoy using an extensive vocabulary, which makes them fun to talk to (though they'll do best chatting in a small group). If they are linguistically inclined, they'll prefer written communication...as long as it is not handwritten! Email or typed notes would be ideal and they might do well working in your office, handling correspondence, or taking notes on a laptop during committee meetings. Many with Asperger's have superior visual-spatial skills and become excellent mechanics, builders, or artists. Others are more math oriented and may excel in accounting or inventory control. Most do have a tendency towards attention to details and this hyper-focus can be channeled to productive use in all work areas, leading to great performance and exciting new innovations (Einstein? Da Vinci?). With a bit of help in setting up a schedule and discussing work expectations, they'll find comfort in following the routine, and you can count on them to work hard when needed, as long as they also get the quiet alone time they need, before and after.

### *The Bad*

On the other hand, there will be some challenges, too, especially in the area of emotions, which are largely a mystery to people on the autism spectrum. A "typical" person can notice a frustration and then say, "I feel frustrated." The ASD person is more likely to become visibly and physically agitated, perhaps jumping up to pace or cry or yell, even though the same situation seems mild to others. With practice and support, they can get much better at interpreting emotional content and expressing themselves, but it is a learned skill that never quite feels easy. Before they can be effective in a conversation, they will need time to mentally prepare, and may use their stock phrase

almost like a mantra: "I'll be glad to talk about that with you, but I need to think about it first and get back to you." This is a socially appropriate way they have learned to buy themselves the "think time" that they need. Rushing them into a conversation usually ends badly for everyone.

Some ASD people may also have a "stimming" behavior that takes some getting used to, perhaps tapping a pencil constantly, fiddling with their hair, flapping their hands, like clapping fingers with one hand, or playing with a piece of string or a squishy ball. These self-soothing behaviors should be accepted calmly, unless they are so odd that they cause problems. In that event, some mentoring by a good friend can help guide the person towards a better time, place, or way to relax, and/or help solve whatever underlying problem may be causing anxiety. Others may have an odd "special interest" such as trains or ceiling fans, that they find relaxing to constantly learn more about, after their community work is completed for the day.

The comfort they find in routines, schedules, and rules is balanced by the discomfort they may express during times of change—especially change that is abrupt or unexpected. The advance planning and good communication that the ASD person requires benefits the whole group, by developing the community's culture to include those habits.

### *The Different*

The rainbow, with its spectrum of colors, is the symbol of hope for people with ASD, and the catchphrase "different is the new normal" sums up this new way of being in the world. Each person you meet will have slightly different strengths to offer and slightly different needs that must be met to let those strengths be expressed to their full potential. Each one will have had different experiences (often negative) in their previous home, school, and work environments, that will affect their ability to trust you and the new environment in your community. But with compassionate communication and a common goal, the Aspies can be important members of the new world we are creating together. ❁

*[Redacted] lived in a rural commune for four years and found her niche in the garden and in helping the group run smoothly by taking good notes during meetings. She can now be found online at [Redacted] and various other places.*

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## To the Doctor...or Not?

An undiagnosed life can be very frustrating; you may spend many years of life feeling different, but never quite understanding why. You may end up with medications that you don't really need, or find yourself in jobs or social environments that will never go well despite your constant best efforts. You and the "typical" world just seem to grate on each other's nerves, for no really clear reason.

## Self-Diagnosis

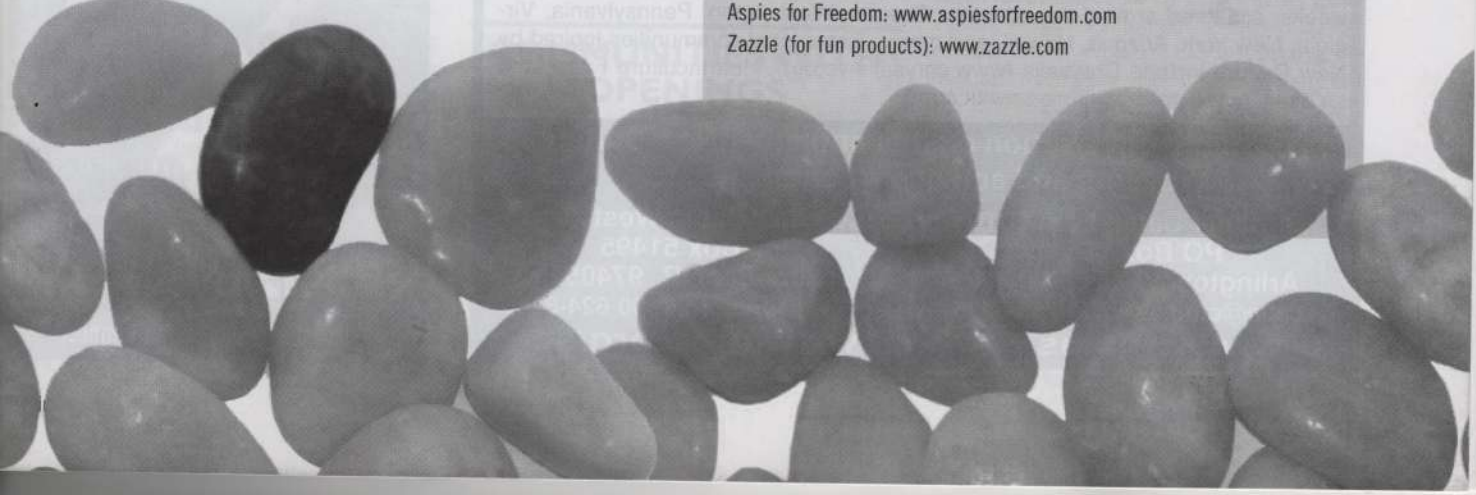
Read books by reputable authors, visit their websites, pay attention during school meetings if your child is being evaluated, explore self-assessments in books or on the internet. If you realize that you, too, would probably qualify for a diagnosis, this can be an exciting moment, even if you don't actually get a medical diagnosis for yourself. With the new term, you know where to look for the support you need. You can learn new coping skills, realize the importance of choosing your career appropriately, set up your daily life in a way that is good for you, and in general start to feel better about yourself.

## Medical Diagnosis by a Doctor

This can be extremely helpful, especially if the person is a child in public school. Without this, the special education department is closed to you, even if all the teachers working with your child know that he or she needs those services. The doctor's signature can be necessary to get school services, medications for co-existing conditions, government assistance, free medical care at high quality hospitals, tutoring arrangements, aides in the classroom, and many other kinds of help. Sadly, children who are able to get by during the early years of school may not get the services that everyone knows they need, until they do eventually begin to fail classes or get in fights or have other serious problems.

## Suggested Authors and Websites

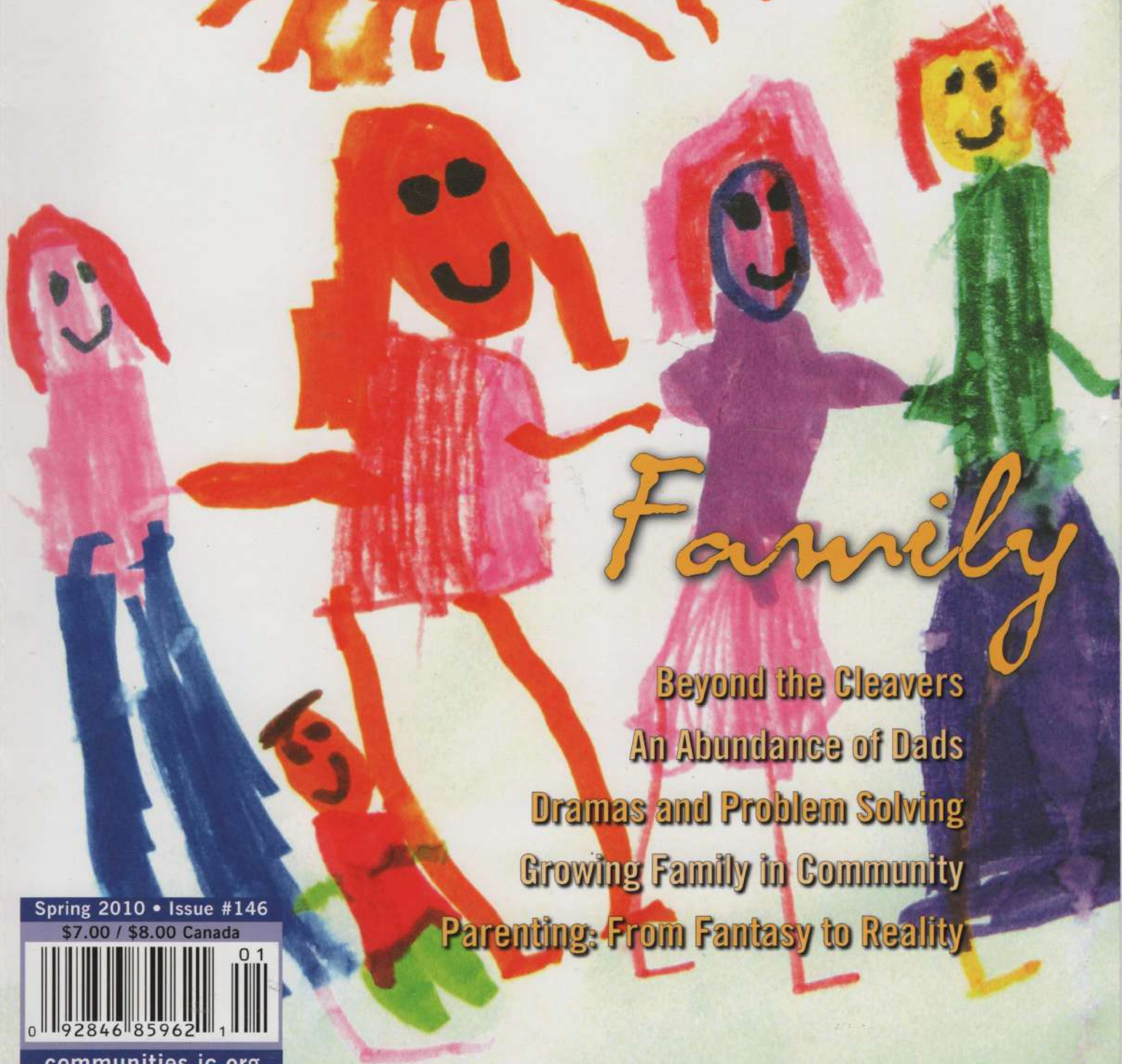
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