Autism Advocacy in the Community: A Parent Perspective

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Gene's current advocacy efforts are focused on transition and adult services, including the Advancing Futures for Adults with Autism effort, led by Autism Speaks and partner organizations. Gene also helped create a national consortium, Agricultural Communities for Adults with Autism (ACAA), which is focused on promoting the development of non-urban, community based employment and housing models for adults with autism spectrum disorders.

Gene and his wife, Lynn, live in Chicago and Michigan with their two sons, the eldest of whom has autism.

The question “Can’t you control your kid?!” The dreaded looks of disapproval. Unsolicited input to “improve” parenting skills or even suggestions to just not come back. Sadly, these kinds of interactions are all pretty common in our community. Sometimes they can even escalate into headlines. Bad experiences in the community can cause families to feel isolated from, rather than engaged in, common community activities. As a parent advocate for nearly two decades, I’ve been there. But over time, I realized that advocating or speaking up for kids with autism in our communities, rather than avoiding problems, leads to positive change for everybody.

Autism Speaks is very engaged in many ongoing “big picture” advocacy initiatives that revolve around things like public policy and legal rights, access to (and the development of) evidenced-based medical and therapeutic interventions, financial supports, housing and employment issues, the fight against discrimination, and a host of other efforts. But what about when it’s not about advocating to positively change the world for all of us? When it’s just one or a couple of us who want to have the most positive experience possible as we navigate beyond our familiar and usually predictable homes, schools, or jobs and out into our local communities?

Public transportation, stores and service providers of all types, places of worship, entertainment venues, lodging establishments, parks and leisure spots (to name a few) are all spaces “in the community” that can pose some serious challenges for people with autism. Challenges can include unpredictable social interactions and possible sensory overloads, even “meltdowns” that are difficult to manage. The key to positive inclusion in all of these community spaces is detailed planning and personal advocacy to ensure a smooth process, and avoiding (or mitigating) challenges when they do appear, which they most assuredly will at some point.
Planning ahead can’t be overemphasized and advocacy should always be part of the plan.

We all want terrific results, but before we get into the details of your plan, it is important to remember that bad days do happen sometimes. If in spite of all of your effort, your goal is just not going to be achieved that day, a smart move can be a short term retreat (options for which should also be in your plan) in order to preserve the possibility of a positive community activity in the future. Don’t let your plan’s design become an ordeal to be endured. Be flexible.

Now, let’s think through the community activity. Is the goal of the trip to visit someone? To run a typical errand? To go to a show, visit the zoo, or just walk in the park? Think through each step and consider whether there are potential stresses that may impact or impede your movements or activities (fare collection, security checks, lines, transfers, etc.)? Consider all of the potential issues that could develop (delays, noise, crowds, weather).

Next, consider any adjustments you think might help you continue your activity on a positive path if something were to negatively impact the plan (and your goal). Things go wrong all the time, but it is best to consider them ahead of time, rather than “in the moment.” Might priority access, a quiet space, slower pace, or extra time help? Could extra on-site assistance help you smooth out any potential bumps? As an aside, many of us do carry an “emergency” kit when we venture out in the community. Our family’s is an iPad (favorite movies and shows loaded) with earphones, books, and a few action figures. But we use it sparingly. Being a part of the community means being “unplugged” and connecting the old fashioned way! This type of “connection” is where the advocacy part kicks in.

Most organizations and service providers in the community, especially larger businesses, have some type of customer service component (often specialists on their staff) available to assist you and others with special needs or requirements. But it is critical to call them to plan ahead. Sharing your concerns and information ahead of time is essential, even if it’s something like, “I’m accompanying a child with autism, a developmental disability. We’re planning to do ____. I don’t expect I'll need help but if I do, are there any suggestions, resources, or staff you may have available to help me?” Most “people-focused” organizations, from the Transportation Security Administration (TSA) at the airport to Disney Amusement Parks to the Cineplex at the mall, have policies in place designed to assist people with disabilities or those with special requests. If you reach out to them ahead of time, you are successfully advocating. It isn’t difficult to do.

But do keep in mind that accommodations, from the perspective of service providers, aren’t always available on demand (especially at peak usage times) or individually tailored. Gauge whether the organization seems responsive to your requests. If their current policies don’t make sense to you, as an advocate you are well within the realm of reason to ask to escalate the matter and sit down with their management. If that doesn’t work (and some folks may be inflexible), that’s a good time to look for support from larger established advocacy organizations like Autism Speaks. You’ll likely be directed to people who advocate professionally and can help you address your issue.

Here’s a quick example of how really basic community advocacy helped my family some years ago. My son absolutely adores babies. He wants to look at them, touch them, hold them, and speak to them. It is way beyond a “typical” curiosity. But this poses some big issues. Parents are likely to (understandably) “freak out” if anyone, including a child or adolescent, makes an abrupt approach to their child. There are hygiene and health issues, too. Now, consider that infants are everywhere in the community. Babies in the neighborhood, at the store, at the playground, and especially at the pediatrician’s office! That’s where we had a big issue.

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Even when my son was small in size, the wait to see the doctor for a wellness visit invariably involved an epic struggle to keep him from rushing at the babies around him. When he was small, scooping him up was usually (if noisily) successful. Then he got bigger. A lot bigger. We tried our best blocking moves, but they sometimes proved inadequate. He scared some moms. He grabbed some babies. No one was ever hurt but my wife and I were mortified. We thought the office staff couldn’t help but notice (and probably got some complaints). But what could we do? Skipping checkups was not an option and every other practice is set up the same way (with a big, common waiting room.)

The eventual “solution” turned out to be just speaking up. We approached the practice to explore a strategy to provide us with “options”. We spoke with the pediatrician, nurses, and staff. It turned out that they weren’t even aware of our issue! They were jammed with filling out insurance forms, keeping the patient flow moving and the physician on a tight schedule to notice our regular distress in their waiting room. We asked if they could accommodate scheduling a first or last appointment of the day when the waiting room wasn’t so jammed. Were there other “down times” during the day that they could recommend? In the event that wasn’t possible, could they make an exam room available on short notice to whisk him into if he was having a tough day? The answer was a resounding, “Yes, sure we can help!” As a family, we’ve worked hard to positively model and reinforce socially acceptable behavior around babies (and still do!) but now we had a plan in place in case that didn’t work. Visits to the doctor became a lot less stressful from that point on. All due to speaking up...advocating.

Importantly, this experience really hammered home a critical point. If the staff in a leading pediatrician’s office, where they provide care for more than a handful of kids with autism and see other behavioral challenges, couldn’t “see” our difficulty and didn’t “volunteer” a solution to us, who would? We learned right then and there not to “expect” automatic accommodation for our son in the community (even if it seemed to us like “common sense”) and, instead, to advocate for it.

Start with the expectation that very few in the community at large will understand the supports or specific accommodation your child needs. But also start from the frame of mind that most people are happy to help you if they understand your request and are able to accommodate you without major changes in the way they operate, especially if they are given the time to respond.

The community postal clerk, checkout person, security guard, waiter, flight attendant, theatre manager, passerby, pastor, or even first responder may not have a nuanced understanding of autism or the behaviors associated with the disorder. But because of huge social progress on disability issues over the past few decades, most people understand that when you raise an issue of disability, they need to pay attention. I think this is especially true among young people.

My generation had very little education about, or exposure to, people with any type of disability. Today, diversity (including disability) is included in most school curriculums across the country. It’s now typical (and the law of the land) for kids with disabilities to be included in classrooms and school environments. So in many ways, young people are the best folks in the community to ask for help if an issue arises. They “get it”, so make it a point in your advocacy efforts to include younger folks.

I’ve successfully used this “planning plus advocacy” approach hundreds, if not thousands, of times since that visit to the pediatrician. It’s worked superbly with airlines, the toy store owner, librarian, taxi driver, security guard, greenmarket, neighbors, and so many others. There have been very few exceptions. Opening up to advocate has added benefits. It gets us talking to new folks, which is a good thing for busy parents and caregivers, and increases autism awareness and acceptance in the community.