

# Listening to Parents

## *Understanding the Impact of Autism on Families*

JAYNE LYTEL

Washington, DC

*Editor's Note:* No two families cope with the diagnosis of a child's developmental disability in exactly the same way. In the essays that follow, three parents share their experiences with the diagnosis and treatment of an autism spectrum disorder. Listening to parents describe the impact of autism on their families reminds us that each child and family bring a unique set of circumstances into the doctor's office, therapy room, or early intervention program. Respecting individual differences, building on family strengths and dynamics, and developing meaningful and caring partnerships with parents offer the best chance for effective early intervention services that will make a lasting difference.

### **Coping With a Diagnosis: What You and Your Family Are in For**

by Jayne Lytel

**S**OON AFTER HER son Leo's first birthday, Jayne Lytel noticed that something was not quite right. Leo was subsequently diagnosed with autism, a label she fought ferociously while immersing herself in a search for appropriate treatments. After 4 years of rigorous and sometimes grueling interventions, he no longer meets the diagnostic criteria for an autism spectrum disorder and no longer receives therapy. Today, Leo is highly verbal, attends a mainstream school, and is thriving. The following excerpt is adapted from *Act Early Against Autism: Give Your Child a Fighting Chance From the Start*, which debuts March 4, 2008, published by Perigee.

After Leo's diagnosis, the hardest thing was trying to live like a normal family. The diagnosis had changed our lives profoundly. It was difficult to engage in social activities with the boys when we were around parents with typical children. Either David or I would need to be on "Leo duty" to keep him from exploring—a polite way of saying "wandering off."

When our older son, Lucas, 4 years old, received a birthday invitation from one of his classmates in September 2001, I decided to take Leo, then 27 months old, to the party while David stayed home. I was as eager to go as Lucas was. I longed to chitchat with other

adults, and Lucas, naturally outgoing and gregarious, was in the early stages of discovering what parties were all about.

Leo, on the other hand, did not comprehend the meaning of party, and I didn't prepare him for the event. I didn't think he'd understand or that it would make a difference if I told him what to expect. I often carted him around like a handbag so I could get my errands done. I knew that I could have told him we were flying to the moon and he would have had the same reaction as if I had said we were going to the grocery store.

The challenge Leo faced in social situations had not yet become evident to me. I didn't think ahead about how Leo would react when placed in the company of 10 boisterous boys who were 2 years older than him. Taking him was not a test to see how well he'd do in the company of other children—just a case of cluelessness on my part. When we arrived, the front door was unlocked, so we walked into the foyer. Karen, the mother, came to greet us. She looked younger than me, a plus-sized woman with her hair worn in wispy black curls, and her lips and nails painted vibrant pink. Karen looked at me, then Leo and Lucas, and then back at me. She took the present I handed her while I blurted out, "Leo is autistic."

There was an awkward moment of silence and a stunned expression on Karen's face

before she adjusted to crack a small smile. "Well, I'm glad you came," she said, her voice tightening. "Let me show you the playroom."

Looking back, I confessed to Karen because I wanted her to be extra kind to me, as people do when a loved one dies and they crave sympathy. It had only been 2 weeks since Leo's diagnosis, and I couldn't think about much else. I had suffered an enormous loss that was very, very real and was in shock, still grieving and adjusting. The birthday party created another episode of fresh grief because it reminded me that Leo would not celebrate his fourth birthday surrounded by young friends. Again, I felt that crushing loss of hope.

Karen led us to the playroom. I now realized the obvious—that I should have left Leo at home with his father. Leo squirmed and broke loose from my arms. All of the other children ignored him. I can't blame them. They didn't know Leo. They were a bunch of 4-year-olds whose own social skills were pretty rudimentary. I couldn't stand to see Leo ignored, so I started playing with him the best I could. There were heaps of Fisher-Price toys strewn around the room. Leo showed little interest in them and constantly headed for the open door that led to the kitchen. I felt uneasy and trapped and couldn't wait for the party to be over.

The time I spent in the playroom felt like an eternity when it was probably no more than 45 minutes. Karen didn't check on me. No one did. When it came time for lunch, Karen opened the door to the playroom and called the children. I told Lucas to go and eat.

Alone in the playroom, I worked to play with Leo. And it was work—to get his attention, and to hold his attention. I blocked him from running upstairs, but he got away and I



PHOTO: LEO LYTEL

Left: Leo Lytel's first self-portrait, drawn at age 5. Right: Leo's self-portrait drawn 1½ years later.



PHOTO: LEO LYTEL

had to retrieve him before he made it to the top of the stairs.

Coming down the stairs, I looked into the mirror overhanging the fireplace mantel and saw the reflection of Karen removing the last dirty plate from the table. I thought now would be a good time to make an appearance. If there was one thing about Leo, he loved cake, especially chocolate. When Leo and I entered the room, Karen was lighting the candles, and everyone waited for her cue to sing “Happy Birthday.” We rushed to sit down on the place-holder chair that remained as all eyes shifted to Kevin. After an off-key rendition of the song, Kevin made a wish, and the table erupted in cheers and applause when he blew out all his candles. As Karen was passing out the cake, she groped for words to ask if Leo would like a piece. Flustered, she stopped in mid-sentence and finally placed one piece of cake in front of us. I sensed that her brief observation of Leo had led her to believe that because he couldn’t talk or interact, he wouldn’t notice, or care, if he didn’t get his own piece of cake. Without asking if we’d like another fork, Karen moved on to the next person.

I was too stunned to assert myself and ask for another one. Leo and I alternated eating bits of cake sharing the one fork. I sensed his pleasure as he relaxed against me and ate the sweet icing. I rubbed my tears before they became evident and felt as though I had died.

After we ate our cake, we left in a hurry. I forced myself to thank Karen for inviting us and strode, head down, seething, enraged, out the front door. My entire body shook, and I did not look back.

Being treated like an outcast was unprecedented for me and struck a nerve that I

did not know existed. I did not understand how Karen could have been so cruel. I wanted her to have a child with special needs so she could feel what it was like. But also I’d been raised with my parents’ usual prejudices against people who were disabled, who make us normal people feel uncomfortable because they are weird, incomplete, maybe even contagious. And now, by some Karmic accident, I’d been grouped with the abnormal. The idea that from this point forward the world would see me for my wounds and not my bravery left me in despair.

I never brought up the incident with Karen since we were not friends, and I didn’t know what to say. Although forgiving is central to my Christian faith, I have not entirely forgiven her, and I cannot forget. For years I carried deep, unresolved feelings about the party, and, these feelings would rise again with every birthday invitation Lucas received and then again when Leo entered preschool and started receiving invitations. Birthdays, for me, no longer meant carrot cake at the cherry dining room table in the house where I grew up.

Instead, I felt what rehabilitation counselor Simon Olshanksy termed “chronic sorrow,” meaning a continuous grieving process that persists. Somewhere out there, perhaps—after we found a new house in a new city, found schools and services, after Leo began to show signs of overcoming some of his challenges, after I got back on a regular exercise schedule and we were surrounded by a tight-knit social network, after a good long string of accomplishments—joy might return. But it seemed to me on that day of the party that triumph was a very long way off.

Even years after the birthday party incident, I cringed every time I had to wait in the pickup line at preschool and make small talk. What did the moms think of me and my son? I imagined it went like this: “He cries all the time. What’s wrong with him? We won’t ask him over for a playdate.” Leo is my son. I love him, and I’m desperate to help him work through his frustration. If you only knew what we’ve been through. You’ll see. I’ll show you. Leo will show you. He may have a testy temperament, but he’s an exceptionally bright child, maybe even a genius, and I’m going to get him out of this school and find a classroom of children that will revel in his colorful use of language and appreciate his bravado. He won’t be like this when he’s 16. He can’t be like this. I’m counting on him learning how to work through his frustration—for my sake. I need a life, too.

After the blow of the diagnosis, you’ll move through the seven stages of grief, which psychiatrist Elisabeth Kübler-Ross described as shock or disbelief, denial, bargaining, guilt, anger, depression, and acceptance and hope. Your journey through these stages will occur at your own pace and in your own way, often without a defining line between each stage.

As you cope with an emotional stew of feelings—frustration, exhaustion, anxiety, rejection, stress, and possibly depression—your natural defense mechanism to “compartmentalize” your thoughts might kick in. Compartmentalizing is a psychological term that means to separate different aspects of your life into baskets in order to focus on a task. For example, you need to separate your thoughts from your daily tasks. Spend a half hour making telephone calls, the next hour filling out forms, and another block of time doing something else. It boils down to focus and not letting your emotions intrude on what you’re doing. Planning your day like this sounds rigid, but you’ll accomplish more. If your child is newly diagnosed, your first task is finding a team of trusted experts who can help you weigh the pros and cons about educational and treatment programs in your area.

Finding the right team will help you feel more empowered and relieve some of the stress. But securing that team is stressful, as you’ll be taking several actions simultaneously—calling experts, running into bureaucratic policies, conducting research, taking notes, keeping records, visiting programs, fighting with your health insurer and/or school district, making decisions, and balancing the needs of other family members. You might feel, as I did, that you’re being evicted from a life that suddenly bucked you off into a new and unknown world.

In coping with my son’s diagnosis and treatment, I tried to follow the advice of Leo’s psychologist. On every visit, she



Leo Lytel, age 3, looks at himself in the mirror.

encouraged me to make time for myself and not feel guilty. I followed this advice, leaning more heavily on the things I always did to relieve stress: I ran or watched television or got that manicure or I drank wine with dinner. I didn't use any of these activities to avoid helping my child, such as taking up long-distance running, adopting a TV addiction, or drinking a whole bottle of wine at a time. I found it difficult, however, to make time for other family members, especially my older son, who felt confused and frustrated because I paid so much attention to Leo. Doing something special with him, such as taking him to a movie or to Payless for new shoes, was something that I wished I had more energy for.

My husband and I didn't see a marriage counselor, though I could have used guidance to help me communicate better and even argue in a healthier way. But in the end, when we needed the most help, we couldn't afford it, and there never seemed to be enough time to schedule yet another appointment. As it was, we settled for going out when we could find a babysitter, which posed its own set of challenges.

Experts say that the central family dynamics are reordered in all families confronting the illness of a child, whatever the diagnosis. His or her care becomes the axis around which most everything else revolves—shopping, meals, weekends, schools, vacations, and the rest of the details of daily living. If your “damaged” child is high functioning, he or she soon learns how to manipulate the situation to get more good things and to avoid most bad things. Even if your other children start out sympathetic, there is a time invariably when their goodwill runs out and

they resent all the “yeses” their sibling gets at times when they get “nos.” This phenomenon also needs to be addressed early, as early as you can see it developing.

It is useless to be told to be fair to your children in their conflicts with one another. Of course you try to be fair. However, when one child is getting most of your time and attention, when you have restructured your life to be that child's full-time assistant, and when you react to the child's tantrums with soothing rather than discipline, your other children are bound to be jealous. There are no instructions I can give on how to handle this except to say you need to know this is coming, prepare for this early, and expect it to be with you for as long as your child is in therapy. But if there is one piece of advice I can press upon you, it is to make a special date on a regular basis with your typically developing child—take him to his favorite diner, buy him a treat, hug him, but most of all talk to him and try to get him to explore his feelings with you. Your child who does not suffer from language delays or poor social skills needs intervention, too.

After Leo's diagnosis, I was more or less blind to the fact that my social network steadily disintegrated. My neighbor had a son about Leo's age who was developing normally. While I appreciated her company, I bristled at anything that could be considered a comparison between her son and mine. We saw less of one another. The same thing was true, more or less, with other parents of young children who were friends and neighbors. My already small network of friends entirely transformed itself as I became close to other women with children in treatment. Some friends deserted me, and others passed

judgment and made hurtful comments. I understand that they just didn't know what to say, and there wasn't much I could say in return. I could educate them on the disorder or ignore the comment.

My one-on-one friends and therapists became my support group. As I spent more and more time in the company of mothers with children in therapy, they became my friends and the moms I would set up playdates with. Most of the time, their children faced challenges far more overwhelming than mine. The mothers were adjusting to children with lifelong disabilities and who in some dimensions were never going to grow up. This should have terrified me since it was precisely my worst fear. However, I had confidence that Leo had only a few years of therapy before we could stop, and it reassured me that he was closer to normal than those other kids, which allowed me to cope. I am not proud of this, but that's how it was.

You may find comfort by attending a support group for parents and siblings of children with autism, which is what I did in the beginning until I developed my own network of friends. I never got involved in an online support group but can see how this would be useful, especially if you live in a remote area. Whether you attend a support group or call another parent, I think the interaction with other parents is exceptionally important.

I also sought and received constant reassurance from all of Leo's caregivers that I was doing the right thing. After Leo's therapies, I'd block the door so they'd have to tell me something hopeful before we left. Just a few positive comments about Leo helped me heal.

Sometimes, professional help was diverted from treating him to treating me. In particular, I used as much of Leo's time with a psychologist to get her to listen to me and my problems and, above all, to reassure me that I was doing the right thing and he was getting better. Some sessions were devoted to helping me improve my play skills, recognize Leo's play themes and feelings and help Leo think logically, play symbolically with another child, and deal with his fears when he conjured up scenes that involved good versus evil. We also talked about Leo's relationship with his brother and father. In retrospect, maybe I should have gotten my own therapist, but no one knew me or my child as well.

I also never tried medication to control anxiety or help me sleep, but it might be right for you. Other than a few short visits alone to my parents to wind down and gain some perspective, I never took an extended vacation from my case management duties, but that may well be a good thing to do.

I didn't have an affair, buy expensive items, engage in big home improvement projects, get my mother to move in to help

out, get pregnant to give Leo a younger sibling, adjust the household's diet to exclude foods that some parents said would improve the symptoms of autism, sell my house and use the proceeds for Leo's therapy, or a dozen other things that might have happened. To me all those things were bad ideas, but you may find yourself pursuing one or more out of fear, discomfort, frustration, or necessity. The right way for you to cope is unique to you. Whatever ways you have of managing your own mental health will be as important to your child's course of treatment as anything else you'll do to help him or her.

**JAYNE LYTEL** *founded the nonprofit The Early Intervention Network: Enabling Families to Act Early Against Autism ([www.actearly.org](http://www.actearly.org)) in 2007. The mission of the Network is to promote policies and practices that raise awareness of the early warning signs of autism spectrum disorders and expedite treatment for newly diagnosed children.*