



# SPECIAL TIMES

Community Therapeutic Day School

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## REFLECTIONS ON PARENTING A SPECIAL NEEDS CHILD

*I* am a mom, I love my daughters dearly. One has been labeled “special needs”. My life is juxtaposed. I am a better person, for my daughter Maura brings great joy to all who know her.

I become more knowledgeable.  
I find strength I never knew I had.  
I meet my best friend.  
I get divorced.  
I grow stronger.  
I have set-backs.  
I celebrate small victories.  
I am afraid, determined, angry, depressed.  
At times I find peace.  
I worry what others think of my parenting.  
I endure criticism.  
I am called a saint.  
I feel alone.  
I laugh a lot and cry a lot.  
My other daughter has needs too.  
Some days I feel crazy.  
I wonder if I can keep doing this.  
Relationships are broken, but joyfully some are repaired.  
I am judged constantly by ignorant critics.  
I've learned acceptance and compassion.  
I can trust.  
I pray, I hope, I dream.  
The possibilities are endless.

*by Jane McNulty*



*by Lian*

*“One does not discover new lands without consenting to loose sight of the shore.”*

*by André Gide*

Nicholas was diagnosed with Asperger's Syndrome just after his third birthday although I had mostly figured it out for myself several weeks before. It just sat in me, this knowledge. As a child, I was scared of my closet and I remember feeling that same feeling: there was something unknown waiting in there. Only this time, I opened the door and a little face looked out.

I turned to my mom one day, shortly before the trip to Children's Hospital, and said "You know, they're going to tell me this is autism." My mom looked at me gently and said, "The thought had occurred to me too, sweetie..." And so it was.

As I look back, I know that my response to grief and worry was an obsession with figuring out the future. As if, having realized I could not control the world, I wanted at least a sneak preview of all the good and bad that was in store. I was a fury in those days. I skipped denial, bargained briefly over the name of this disorder (if we call it something else, will that make it so?), tried guilt on for awhile—at least being a "refrigerator mother", as mothers of autistic children once were known, gave a cause to the problem—and finally settled on manic action. I read everything, talked to everyone and anyone. Becoming an "expert" was my own version of wearing strands of garlic to ward off evil. I was all flailing and external. Josh, my husband, was internalized and private and seemingly calm. I called him a duck: floating across the waters (while underneath paddling furiously). I preferred to drown publicly.

It is a blur to me now. It seemed grief just sat there waiting to be lived out. Someone finally said to me, "Jane, I think you've cried, but I don't think you've grieved. Give yourself that." So I slowed down and grieved.

I remember waking up crying. I remember feeling isolated. I remember a boundless compassion for my little boy. I remember needing Eliza, my daughter, in my lap and Nicholas in my lap and the feel of curling around Josh just to lie still. I remember the obsessive reading and talking and steeping in autism. And I remember realizing one day that everything was OK. Acceptance is the ultimate evolution; crawling from the primordial ooze onto dry land. Point A to Point Z. Now I am trying to remember how we made the migration.

It is the little things that brought us back, I think. The little daily stuff that crowds together to make up the days: Nicholas' cute face. Eliza looking at him with delight. Progress of any sort. Eliza being Eliza in her own right. Keeping a sense of humor. The value of helping other moms who had just heard the same words we had once heard. And time. You give in to the grief and it lets you give in to the acceptance. You ease back into your own self.

So, the diagnosis didn't stick—not to Nicholas, not to me, not to us as a family. Don't get me wrong, Nicholas still has a recognizable case of something or other, it's just that it matters less. It is just part and parcel of the richness of our lives.

I feel now that I have a sweet secret: our life is infinitely better now than it could ever have been before. We adore our beautiful children and know that each has given us an incomparable gift. We have cleared out the clutter of things that don't matter—and so can live what does. I look back on my grief and it is unintelligible to me. How could I grieve over a wonderful child?



*by Jane Moncreiff*

**I** did not panic or go into depression when I learned that Mitch (his name since July, 1992) was a special needs child. This was because it only became apparent over his first 2 years. Anne, his mother, sensed his situation many months before I did but I was never in denial. Once I'd seen enough evidence, I swung into line. There was no element of shock.

I never felt that being the parent of a special needs child was different from being a parent of a normal child. We did, after all, many of the same things together that any father and child would. It was a matter of degree, Mitch required more time, more surveillance, more repetition, and simply more attention. Also, unusual solutions had to be found at times. For example I am a physical person while Mitch was tactile defensive. But, like many other children, he loved to be tickled. So I'd tickle him, hug him and kiss him at the same time. Soon he was calling for a kiss and a tickle. Thus did we connect.

By 7th grade Mitch was totally mainstreamed though still under counseling surveillance. Seventh and eighth grade were difficult years. Yet it was through that early adolescent adversity that he developed the immense inner strength that remains his trademark to this day. As soon as he arrived in high school he felt at home. He worked things out for himself, while I became his sounding board: arguing, advising, cautioning, but ultimately leaving things up to him.

Poet, pianist, singer, songwriter, baseball player, referee or umpire at school games, actor, social worker with early adolescents, Mitch has the making of a leader. Today he is a political organizer at U-Mass. He is multi-lingual and, above all, he relates to people in any language. He is a child I would have liked had I been his teacher or baseball coach. This fact facilitated my task as a parent for I not only loved him, I liked him. I think he sensed this. Much credit for his success goes to my loyal family and to the CTDS staff. Much as well goes to Mitch himself and his iron determination to blast himself out of his early childhood. *by Larry Lewis*

### **A Journey Through Parent Group**



**P**arent Group, what a simple way to describe it. These are just two words that suggest to the average person, a group that meets regularly and chats about their child's life. But one visit to the Parent Group at CTDS and the meaning of Parent Group changes to one of acceptance, respect, sincerity and growth.

When my husband and I decided to send our son to CTDS, we were primarily sending him there so that he could grow. He needed to learn that he could be in control of his own thoughts, feelings, and actions. By working towards this goal, it is our hope that he will learn to make choices for himself about the kind of life that he wants to lead. What I didn't expect was to learn that these were goals that I would work on for myself at Parent Group.

When I began attending Parent Group, I thought I understood most of what it meant to parent a child with Autism/PDD. Then, I began listening to other parents talk about their children. I never even knew that I would encounter some of these issues with my son. I was so busy just getting through the day, I wasn't able to see the future. In their own special way, this Parent Group gave me a wonderful window to the future. I didn't even realize at the time what an opportunity that was. I was frightened about our future. I thought that we would have to forge ahead alone. I thought that I would always seek the advice of "professionals" when I had a question. Little did I know I was seeking the advice of professionals. You see, Parent Group participants *are* the professionals. I learned how to make decisions for my son. I learned how to grow as a person. This was a place where I was accepted, respected and made to feel welcome. I am not the same person that I was when I first attended Parent Group. This group helped me to make decisions for myself, *about* myself. It helped me to get on my feet. By doing that, I could help my son get on his feet.

I no longer attend Parent Group because I am now working. I miss seeing everyone there. I know that I can call any one of its members for advice or even just a shoulder to lean on. That's the beauty of Parent Group. You never actually leave Parent Group. It becomes a part of you. It stays with you forever. Parent Group helped me to learn to accept my son's challenges, my own challenges and my family's challenges. I don't feel sorry for myself anymore. I don't feel cheated. Instead, I feel confident and truly blessed.

*by Deborah Lagasse*

Parenting a child with special needs not only offers unique and often difficult challenges, but also great opportunities and enormous rewards. I would like to share with you a small part of my parenting journey.

At the age of five years, my daughter Alison was diagnosed with a thought processing disorder. Those seemingly innocuous words confirmed my greatest fear - we could not communicate. I felt totally inadequate as a parent.

Our family searched frantically for help which became realized when Ali started at CTDS in 1988. With the assistance of an extraordinary staff we learned to help Ali choose to connect with the real world, for she had created her own worlds that made little sense to us but were very real to her. The "Time Out Chair" became a safe vehicle to help her process her anxiety and at the same time it gave us control over her behavior that was so disruptive in our daily lives. Her behavior included such things as hysterical outbursts of uncontrolled laughter, jumping up and down and flapping her hands, echolalia, sleeplessness, great anxiety and not being able to distinguish fantasy from reality. As Ali's behavior became more controlled we were able to start communicating. We had to learn to speak using language that was clear, precise and not too wordy. We set up a system so that we could communicate through non verbal signals to help avert loud embarrassing comments by Ali. We also prepared her for new situations to alleviate anxiety; we were very firm about how we expected her to behave and we used the "Time Out Chair" when those expectations were not met. Of course, Ali's behavior was greatly misunderstood by the general population and we were constantly having to explain that "she doesn't lie", "she doesn't mean it", "she doesn't need it", etc. The fact was, she just didn't understand it!

Today, Ali is nineteen years old. She still needs a lot of preparation for new situations, clear and precise language and a lot of help to process her thoughts and emotions. However, she is pure of heart, joyful (when not troubled), patient, kind, loving, persistent, polite, self confident and a talented singer whose voice was discovered by a teacher who was looking for Ali's "gift", and found it! She now leads sing-a-longs at nursing homes on a regular basis, sings solos at parties, school functions and conferences. Amazingly, she does all of this with no stage fright!

It seems ironic to me that for a child who had such difficulty expressing herself verbally she can now do so naturally, using her voice and words of song to move the emotions of others. It is a real lesson to me as a parent that we should always be watchful for the hidden voice or talent of our children. It is particularly challenging for us as parents of children with special needs to be watchful for these talents. We should try to be open to the fact that the mere uniqueness of our child's personality can guide the way to their special gift or gifts.

Just keep on looking. I'm sure you'll find it.



*by Jayne Hamel*

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ANNUAL ALUMNI PICNIC, MAY 4th 6pm-8pm

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