

10 Ways to Make a Difference for Your Grandchild with Autism

by Jennifer Krumins

I am told that grandchildren are one of life's greatest blessings.

But, I have also learned that life doesn't always deliver its blessings in the package we expect.

The diagnosis of autism is, for many, a jolt into a new world. A world with more questions than answers. A world filled with fear, doubt and disappointment, at least initially. The diagnosis tears at our hearts and brings the future crashing down (at least for a time).

Perhaps, you have awaited the arrival of your grandchild for months, maybe years, and now the gut-wrenching truth is almost too painful to bear. Your adult children are suffering. Your heart may feel broken; the future seems grey and uncertain.

There must be a way to ease the pain. You want to help. In fact, you may feel desperate to help. But, how?

Truth be told, grandparents play a critical role in the life of a family navigating autism. You have the power to make life more manageable for your children and your grandchild - or you can undermine their challenges and exacerbate an already fragile situation.

What do you need to know in order to be the support you long to be?

1. Be a model of compassion, affirmation and hope

Listen, affirm and avoid offering quick judgments and /or solutions. What parents need most is to be supported and to feel affirmed that they are good parents and they will be able to cope; they are not alone. Unsolicited advice, no matter how well intentioned, is often counterproductive. As much as it hurts, there is no quick, hard and fast solutions. But, a warm, compassionate and listening ear will go a long way to providing the support needed to cope.

2. Accept and love the child 'as is'

The grandchild you have may not be the one you imagined. Perhaps, your grandchild is detached, unpredictable, and hard to connect with. Acceptance and unconditional love can be tall order when you are in public and a full-blown tantrum is underway! Remember, this is not a child that is misbehaving; he or she needs to tell you something and is not capable of it – even if words are possible. Loving our children means interpreting their behavior to find the message behind it. Loving our grandchildren means being more concerned about what the child is thinking and feeling than what others are thinking.

3. Decide to be positive and hopeful

Human nature prompts us to search for causes and reasons - something or someone to blame when life seems unfair. In the larger picture of your grandchild's emotional, physical and intellectual growth, negative energy is simply wasted energy. Positive energy seeks to learn, to understand and to support what is – rather than lament what isn't. Pointing out mistakes, criticism masked as advice damage relationships, even when unintended. Autism is a neurological disorder. Parents cannot do anything or fail to do anything that would leave their child autistic. Suggesting otherwise is unscientific, cruel and utterly wrong.

4. Be a student of Autism

The goal should be to increase your understanding of the way your grandchild communicates his/her needs. Beware, this may well 'look like' 'inappropriate' behavior from your perspective. But, as you learn how children with autism perceive the world, you will be able to create a safe, predictable and comforting relationship that will nurture a deep connection with your grandchild.

5. Give the gift of time

Don't wait to be asked. Your child's marriage and mental health needs as much attention as does your grandchild. It is an investment for the whole family when you provide the regular opportunity for relief. Gift certificates for movies, dinner, spa, and fitness clubs are a way to "force" a parent to take time for him or herself. Most parents will never quite 'get around' to taking care of themselves. A homemade meal or a house cleaning can go a long way to ease stress. Take care of your adult child so they can care of your grandchild.

So often, life at home is centered on the child with special needs that siblings can get "lost in the shuffle." Special days away or planned activities give siblings the relief that they need from a busy and stressful household. Another option is to provide care for the child with autism so that parents and typical children can reconnect! Siblings need to learn that it is healthy to take a break from caring for a person that needs a lot from us.

6. Build self-esteem and resilience

It is so tempting to do things for our special needs children. We can easily feel that "our babies must deal with so much already," that it seems cruel to allow the child to struggle. However, resilience and self-esteem are born from the effort it takes to struggle and succeed at a task we have not yet done independently! When we adults, rush in to rescue a child too quickly, we actually sabotage the opportunity to develop self-esteem and self-agency! Esteem building grandparents have high expectations and high levels of support for their grandkids with autism.

7. Use Autism friendly communication

"Do you want to rake the leaves with me?" Guess the response. State your wants and needs rather than asking a question. For example, it is more likely that you will get a positive response if you say, "Come rake the leaves with me. You can help me." People with autism are often quite literal in their thinking and if we pose statements as questions, we may get a response that we did not intend. Also, avoid being loud, talking quickly and giving multiple steps. Your grandchild will most likely not be able to process all of your verbal instructions and they may ignore you or become very agitated.

8. A picture's worth a thousand words.

This statement could not be truer than it is for most people with autism. Pictures, lists and diagrams are far more meaningful to most people with autism than are words.

If your grandchild is upset or seems to lack understanding of something it is useful to draw a picture/diagram, list the steps that will happen or use a picture schedule. For example, a list might say: 1) Play at park. 2) Snack. 3) Brush teeth. 4) Bedtime. OR even more specific: 1) Eat snack. 2) Brush teeth. 3) Read story. 4) Sleep. Your grandchild with autism may process the printed word or picture more efficiently than the spoken word.

9. Respect the boundaries and expectations of your adult children

I know, this one is tough – it even hurt to write it. But, unless you are actually raising your grandchild, the fact is, you are not in charge. As humbling as it is, if you want to be helpful and supportive, deferring to the rules and expectations of the child's parents is a must. Raising a child with autism demands a structure and routine that is essential for the child's physical and emotional well-being. Follow dietary restrictions, bedtimes, routines (no matter how odd they seem) and communication guidelines that the parents set. People with autism may have trouble coping with changes in routine, food, sleeping arrangements, toileting, and so on when they are in your home. This is not because they are behaving poorly. This IS NOT a discipline (or lack thereof) issue. It is an autism issue and it needs to be treated as such.

10. Trust that you can make a deep and life changing impact

As grandparents you may feel helpless and completely at a loss as to how to help. In reality, you do have the potential to make a huge difference whether you are physically near your children or not. A listening, affirming and selfless love are what will get your child's family through the challenge of raising a child with autism. A child with autism will lead you to greater personal growth than you can imagine!

About the author:

Jennifer Krumins is a retired teacher in Peterborough, Ontario with 26 years of experience in special education (teaching severely challenged teens with autism) and in the main-stream classroom setting. A mother of three (one of whom has autism), Jennifer is currently building Autism Aspirations Academy, featuring online training for families, professionals and community members who are eager to learn more about Autism and develop the skills and competence they need to serve individuals with an Autism diagnosis.

Jennifer is the author of four books:

Been There. Done That. Finally Getting it Right. A Guide to Educational Planning for Students with Autism: Lessons from a Mother and Teacher

One Step at a Time: ABA and Autism in the Classroom Practical Strategies for Implementing Applied Behaviour Analysis for Student with Autism

Autism and the Grandparent Connection: Practical Ways to Understand and Help your Grandchild with Autism Spectrum Disorder

Une étape à la fois: Stratégies pratiques pour implanter l'Analyse comportementale appliquée (ACA) pour les élèves autistes

Visit Jennifer's at www.autismaspirations.com and www.autismaspirationsacademy.com
or email her at krumins@autismaspirations.com