

## **Juggling Life's Demands and Finding Balance as a Parent of a Child with Special Needs**

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All parents play many roles but now let's think about those same roles for parents of children with deafblindness. Those roles can seem endless at times, and trying to prioritize all the demands might appear impossible because they are all important.

During a parent training I facilitated an icebreaker activity that brought the group into a discussion about what struggles parents face in their daily lives of parenting children with disabilities. When planning this activity I took into consideration a couple of things. First, who are the participants in my audience? Second, what were my goals for this training? I knew the audience was parents of children with special needs and the outcomes were for them to leave with a) an understanding that parenting a child with special needs includes stressful demands; b) how to identify these potential stressors; and c) learn about some strategies for coping and maintaining the balance.

For this activity I laid out a great amount and variety of hats of different sizes, shapes and colors on the table. Each hat was labelled and represented a different role that the person might have to perform in their day-to-day activities (parent, spouse, chauffeur, etc.). I asked them to grab a hat for each role that they play daily, and to start writing the different activities they have to do in order to fulfill those demands. During the first minute or two, I noticed that almost all the hats were gone and that each participant had many hats by their side and they were still writing. Once I started going around the table asking everyone to share and present about their hats, it was not surprising that almost all of the participants shared the same common daily roles.

Once they completed the first part of the activity, I explained for the second part of the activity, they would sort their hats (roles) from the highest priority to the lowest priority. It was amazing to discover their responses confirmed what I already knew from my personal experience. The most important roles in our lives were placed on the lower end of the priorities' scale. Important roles such as being a "parent" (including parent of other siblings) "husband or wife," "sister or brother" and even a "friend" are taken for granted, and many times overlooked and little or nothing is done to nourish them. These roles are set aside until we have the time for them or raised red flags are screaming for attention and impossible to ignore.

This activity had led us to a very rich discussion. Parents were able to open up and share their feelings and frustration of not being able to handle these demands to maintain a healthy family balance while performing these different roles. Even though there is no strict definition for "special needs" there was a clear consensus that a "special needs child" means "many needs" and meeting these needs takes extraordinary time and effort and the accompanying emotional and physical stress can extend not to just to the parents, but to the whole family. (<https://www.psychologytoday.com/basics/stress>).

During my almost 18 years of professional experience speaking with parents of special needs children, I have learned a lot from the many things parents have shared about parenting and raising a child with complex needs whether that includes medical, physical or mental health needs. The greatest lessons have come from my personal experience of being a mother of a child with special needs.

There are many factors of parenting a child with special needs. It gives you the joy of being a parent, but on the other hand, sometimes those joyful moments are overtaken by inevitable reactions to stress from all the demands that come with parenting a child who needs so much support and time. Often times, there is hardly

a moment of peace, until bedtime. In my experience it is also true that our marital relationships and caring for other children are placed in a paused mode. Our social life and self-care needs are neglected until we see that everything is “under control”, and until then, we maintain ourselves at a simple survival level.

I would like to share some strategies that have worked for me and other parents as we’ve coped and to find the balance in the difficult situations and with different roles we play everyday. Please remember that just as every child has different needs, every parent also has their own definition of needs and what works for one parent might not work for other parents.

The following are strategies to consider when trying to balance your daily demands...

1. **Acceptance** - Accepting and recognizing that caring for a child with special needs is physically and emotionally draining, even when we know that we can do everything and at any time. We have to be careful and understand that when we take care of ourselves, our performance will be much better in caring for our love one.
2. **Delegate responsibilities to other family members and friends** — Often times there are people near us who are willing to help. Family members and friends can help with making a phone call for you, run errands, carpool, and organize a get-together.
3. **Use available respite care services** — Using respite services will give you extra hands and free time that you may need to rest or do other important things.
4. **Allocating quality time to other children** — Setting aside 10-15 minutes a day to spend with other children will be beneficial to you and your children. You will experience other type of childcare needs other than “special needs” and your children will know that they are also important.
5. **Be a parent** — It is understandable that all the daily demands of having a child with special needs (medical, educational and physical needs) are great, so it is important not to forget to see them as our children, not clients, patients or students.
6. **Be a wife or a husband** — Many times our marital life suffers tremendously, due to the many demands of our daily life, so it is important to set aside time to spend together for “a date” at least once a month in which you can have some quality time together that you will look forward on a regular basis.
7. **Be yourself** — Most of the time as parents we put our own needs in the back burner and think that self-care is selfish. Understanding our own needs are important and taking the responsibility to make these needs a priority can help achieve balance in our lives.
8. **Have a life** — As mentioned in the previous suggestions, the concept of having your own life might seem selfish to you or others. However, acknowledging that you need to make time for yourself might help you reset and make changes in your routine. Try to restructure your schedule to allocate small amounts of time at first to do the things you like, such going out with friend or doing a hobby you enjoy.

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