

Letting go to let them Grow: Teaching Independence

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When we parents think about our children being independent, we may picture them as all grown up in a happy life, with us hoping that they will find a good job, be part of a community, and maybe even get married. When looking at this future picture, it may seem like “independence” is an event that happens down the road. The reality is that we have already been promoting their independence from a very early age without realizing that we have started the process of letting them go.

Some examples of early independence-building activities are: playing peek-a-boo (covering your face and pretending to disappear), playing chase around the furniture, allowing other adults like grandparents or babysitters around them to care for them, letting them sleep in their own crib or bed, and the very important step of having them attend school. These kinds of activities and opportunities allow your child to understand that you are there for them even when you are out of sight, and to eventually learn that even when you are not there, they will be okay. Although this may seem easy to do in theory, parents of children with special needs often find the process of letting go and allowing their children to become independent to be difficult and stressful, and often filled with serious concerns.



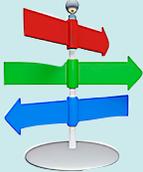
If I think back to when my son Norman was much younger, many service providers told me that we had to set goals and work on different activities to maximize his potential to become as independent as possible. Some areas we worked on were communication, motor skills, independent living skills, socialization, and many more disciplines. But who would have thought that this learning process related to independence was working in both directions? It was helping Norman reach his potential and it was gradually helping me—as a mother—with the process of letting go. I had not realized until later in life that all this hard work had also played a significant part in my own preparation (process) of letting go and promoting Norman’s independence to adulthood.

Parental Concerns

It is difficult to process that most likely my little Abby will not out live me. Even now I see her little fragile body weakening. I often find myself try to cram in as many memories as possible into our lives. At this point she has started having seizures and for that reason alone she sleeps with me every night. I will be my Abby's BFF and I refuse to not enjoy every moment of her life with her. Let's face it – she is stuck with me.
~ Abby's mother

Thinking back to my own experience with this process, I can say with certainty that it has not been easy. There have been many factors that have impacted, influenced and even interfered in the process. Fear can also keep you from starting: fear of the situation your child is in, fear of the unknowable future, and even the fear of parents that by moving towards independence, your child may no longer need you in their life as much.

The following two columns describe how these factors and challenges affected my processes but also will demonstrate some ways that I cope and overcome them:

Factors	Coping Strategies
<p>Medical Issues</p>  <p>Having a medically fragile child dependent on medication and needing medical equipment handy at all times has been emotionally difficult for our family to overcome. Norman's health and well-being have been our number one priority.</p>	<p>Getting as much information about his medical condition and treatment as possible, providing all the medical care Norman needs, and attending all medical appointments and therapy sessions definitely help us ease this concern. Learning as much as possible and knowing we are doing everything we can has been important in coping.</p>
<p>Special Needs Challenges</p>  <p>Accepting and understanding Norman's disabilities has been an ongoing process. As a parent I could not avoid thinking how these weaknesses impacted his life, from playing, learning, self-help skills to be fully independent, etc.</p>	<p>We've used many strategies: learning to look at Norman's strengths vs. his challenges, celebrating his successes, supporting him do things instead of doing them for him, and encouraging and teaching him to express his wants and need to the maximum extent, so that he can be as independent as possible.</p>
<p>Anxiety, Fears, and Stress</p> <p>Having dealt with medical and special needs issues, it was nearly impossible not to add anxiety, fear and stress to the list of concerns: anxiety of the unknown about his health condition, fear that something will happen to him if we were not there, not knowing what to do in case of a medical crisis, and the stress of separation. The sense of security and protection we feel when he is with us was acting as the biggest obstacle to letting go that we as a family continue to manage.</p>	 <p>This is an on-going process. I started to let go of him little by little, allowing gradual separation from the beginning. Making sure that all his needs were met and that an action plan was in place in case of an unexpected difficult situation would definitely help ease the separation.</p>
<p>Cultural Beliefs and Family Dynamics</p> <p>Our family values, traditions, norms and customs sometimes are a kind of barrier or obstacle in the process of letting go and in fostering and encouraging independence, from seeing disability as an illness to the belief that parents should assume all responsibilities for the care of our child. Our family culture shapes how we see the world, our personal values and our attitudes, including perceptions and expectations on what works and what doesn't work.</p>	<p>Allowing my family to be Norman's primary support group, and by letting us be part of Norman's education, medical and social life has helped us all perceive his condition more openly and from different perspectives. We each have a better understanding of his condition and the way we look at Norman's strengths and challenges.</p> 

Factors	Coping Strategies
 <p>Over / Under Protection There is definitely a very fine line that is very hard to distinguish between over-protection and under-protection. On one hand, as a parent you want to provide and respond to all his needs to allow him to live a good healthy and happy life. On the other hand: you want to promote a healthy independent life as much as possible. This has been a battle that I have to fight all the time, the sensation of mixed emotions between separation, safety, abandonment, neglect and overprotection.</p>	<p>As parents, we have to trust our instincts and follow them the best we can. We have to be aware and accept our feelings and emotions that many times do not have to do with our culture. It has more to do with the parent's natural fear to detachment from their child. Knowing that these feelings are normal and that we still have to allow for independence can help a little when we have the chance to step back and think about the situation.</p>

Not all of the above factors, concerns, and challenges apply to every family and their child with special needs. Below are some strategies that might help in many general situations:

- Learn about your child's medical condition, diagnosis, prognosis, treatment etc.
- Understand your child's disabilities/challenges and focus on their strengths instead of thinking about what they can't do.
- Pay close attention to what the child can do independently in order to balance the amount of support needed.
- Gradually separate from your child.
- Recognize how much separation or closeness they need and can tolerate.
- Participation in their educational plans will give you some control over whether or not their needs are being met.
- Help your child learn how to maintain connections to others.
- Although your "protector instinct" is always there, encourage your child to try things themselves first before offering your help.
- Encourage self-determination (check out this resource on self-determination from NCDB: <https://nationaldb.org/library/page/2038>)
- Understand the importance of transitions (check out CDBS Fact Sheet #35: <http://www.cadbs.org/fact-sheets/>)
- Treat your child according to his or her age.
- As much as possible take the role of consultant instead of decision maker (offer help so they can make decisions).
- Set expectations of helping at home (like chores) as with any typical child.
- Use respite care or any other care service to allow both of you some separation and time apart.
- If there are siblings, encourage positive sibling relationships.
- Participate in personal future planning and talking about goals and how to reach these goals.
- Financial planning: think about a special needs trust, Medicaid, SSI, etc.
- Don't rule out possibilities for your child such as work, college or living independently.

And finally, on a personal note: **Start early.** Don't wait until your child is almost an adult to act. Promote healthy independence as early as possible.