



Providing support and information for families of children with disabilities, chronic illness and other special health care needs

Dealing with Ourselves while our Children Grow up!

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Note to self: get started on my son's transition issues. Oh, and by the way, sort out which transition issues concern him and which concern me, and deal with mine right away!

That's the note I should have written to myself when my son Will was about 15 years old. He's now 26 and I've come a long way on both his issues and my own, but I can well remember the fear and anxiety I felt whenever I thought about Will growing up and ending his school career. And through my work with countless families over recent years, I have heard many other parents express these same emotions.

What I have observed is our tendency to allow fear and anxiety to block the way toward planning for our children's adult years. That's why I have come to believe that it's important to examine our fears about our children reaching adulthood, so that we can start to plan for their future. Here's my best attempt to think about our fear of transition, based on my experience and what I hear from other parents every day. Well, why are we so stressed about our children growing up? What about this natural fact of life sends us into a turmoil of negative emotions?

First, I suppose we feel anxiety for any of our children in their teen years, but when you add in a child who may be much less able to take care of himself, protect herself, earn a living, make wise choices, maybe not even tell us when something is wrong, then of course we feel even higher anxiety.

Second, our children's teen years can throw us back into the grief of having a child with disabilities, as we see the milestones that the neighbor's kid achieves with ease. Getting a driver's license, getting a first part-time job, going out on a date, the prom - all the big steps teens usually take may not happen for our children, and that hurts.

Third, growing up means leaving the public school system. When you consider all that a child gets from school - a safe place to be all day where there are opportunities to learn, exercise, meet friends, and gain job skills, then throw in free transportation - we may dread graduation: after graduating, our children may still need these same supports and opportunities but not have a system to provide them. The responsibility may fall entirely on us parents to provide these opportunities and supports - and that rightfully makes us very afraid!

On the other hand, the opposite may be true for some of us, who dread a future when we are not needed quite so much. For years, we have defined ourselves as our children's advocate, care provider, problem

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solver, and biggest fan. How will we see ourselves when we are no longer needed to fill this role? We may have to face changing how we see ourselves, as our children's need for us changes.

Finally I think that a child growing up reminds us of what we fear the most: the time when we are gone and our children with disabilities do not have us to protect and advocate for them, care about their quality of life and ease the way for them. What will happen to my child when I'm gone? That's the fundamental fear we all face . . . and transition brings up that fear.

Oh, yeah, and while we deal with these emotions, our kids' behavior may be getting worse as THEY experience the raging hormones of the teen years!

So how in the world do we find a way to move forward on planning for our children's future, while feeling all this stuff? I discovered one approach recently by starting and participating in a transition support group for the TXP2P staff, all of whom are parents of children with disabilities, ranging in age from 10 to 26. We have met regularly this year to talk about such topics as guardianship, special needs trusts, support programs, going off to college, all the major decisions involved in planning for a person with a disability as they approach adulthood.

At our first meeting, we discussed our fears and tried to imagine a best day and worst day for our children in the next 5-10 years. I went to the second meeting ready to discuss the next topic, resources for assisting adults with disabilities, but what came up right away was more worry and anxiety. We ended up talking about the emotional impact of transition for the first 6 meetings! So I learned all over again how much we need to talk about this stew of emotions.

Another approach is finding a way to hope again. By the time you have been the parent of a child with disabilities for 16 or more years, you have probably faced many disappointments. I hoped Will would learn to talk, but he never did. I hoped a new therapist would teach him to eat independently, but Will still needs help stabbing food with a fork. I hoped Will would find a group of friends in school, but he did not.

To protect ourselves from pain, we quit hoping. And this lack of hope permeates our view of the future. We can't see a prosperous, happy, safe and secure life for our children as adults. I had a great breakthrough toward finding hope when I discovered my favorite parent organization (outside of TXP2P!), PLAN in Vancouver. PLAN's book [A Good Life](#) presented me with a path that still keeps us going. This book taught me to concentrate on Will's gifts and talents, not his needs; to draw others into our lives to support Will, whether we are here or not; and to build for a good life, full of work, fun and people. I now have higher expectations for his life.

I have also discovered something amazing as Will has grown up. *He has grown up!* He acquired all those awful labels during his school years, like a 6-month old expressive level and a one-year old receptive level, but Will is NOT a 6-month old! He acts like an adult now. For example, he has quit grabbing everything on wheels and pulling it around endlessly. He removes himself from situations he doesn't like. He expresses what he needs and wants without resorting to angry behavior. He enjoys people and welcomes them into his life, but not everyone - he is selective. He ends one activity and begins another much more easily than he used to, moving gracefully from one setting to another. He still cannot read, write or talk, but he has the interests, poise and self-knowledge of an adult! I don't think we taught him to act like an adult, though we certainly tried. I think he did this growing up because he wanted to, when he was ready.

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And somehow through this process, I now see him as okay the way he is. I no longer spend a lot of my time trying to "fix" Will. Of course, I worked hard throughout his school years for ways to advance his skills and compensate for his disabilities, and I still look for these opportunities, but my emphasis has shifted to making sure he is safe and having fun. It's a great relief to see him as a person in his own right, beyond my ability or my right to fix.

Finally, the trigger that moved me from anxiety to openness proved to be a planning process. As Will neared graduation, I finally had the courage to ask our school district to do person-centered planning with us. My fear of "what if I have a party and no one comes" had kept me from initiating this process, but *A Good Life* gave me courage, and I decided to act even though still scared and anxious. It worked! I invited a group to join us in planning for Will's future and they came to the party! We did an inventory of Will's life and talked about his hopes and dreams for the future, then created an action plan to work on one goal. We chose the goal of Will having a schedule of meaningful activities, especially a job, to begin after graduation, and the group helped us plan for that goal. Now we began to see the future with hope, accompanied by a small team of people to help us move forward. What a difference that day made! I begin to relax, my anxiety receded, and I could breathe again.

I hope my reflections ring true for you; of course, you are on your own timetable, moving forward as you are able. Each family sees their child and his or her future in their own way. But I also urge you to take your emotional temperature when you think about your child's future. If you break out in a cold sweat and feel paralyzed, think about what is blocking your ability to act. Spend some time considering the emotions connected with your child's growing up. Know that you are not alone in this experience, and allow your child to become your guide.

TIPS:

- ✓ Find someone to support you through this process.
- ✓ Create a positive vision of your child's adult life.
- ✓ Have faith in your child.
- ✓ See your child as okay.
- ✓ Start planning, no matter how you feel.

A Good Life is available at www.plan.ca

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