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Welcome to Holland

Written by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!" you say. "What do you mean, Holland?" I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to some horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy a new guidebook. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's what I had planned."

The pain of that will never, ever, go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

This is my favorite poem that I feel explains so well how a parent reacts when given a diagnosis of a disability for their child. A diagnosis of autism or any disability for your child, impacts the whole family. You and your children, your extended family will forever be in Holland; still beautiful, unique and inspiring but not what you had planned. So you need to adjust - a lot. There are all the doctor and therapy appointments. Before that, it is finally being given a correct diagnosis for your child and the locating the resources that are needed to help your child. Then comes the insurance difficulties; getting coverage, authorizations and somehow paying for all of this. If both parents are working full time, this can cause stress in taking time off from work to get your child to their therapies. Sometimes, one parent may find they need to start working part time or stop working completely in order to get all this done. Research supports that this is usually the mother; who may at times feel resentful for having to adjust her career and with this can come the guilt so many parents can feel over this resentment. This can also come at

a time when the medical bills pile up and income is reduced, so more stress and possibly depression is added to the emotional mix. Fathers and mothers have different coping skills in dealing with this emotional distress. Fathers may work more hours to help the family financially and typically may suppress their feelings. Mothers tend to share their feelings of sadness, anger, and happiness with trusted family and friends, especially those with special needs children. Typically parents are encouraged to find time for themselves, both as partners and as individuals. I sometimes wonder if this doesn't add another level of stress to the parents. Here is one more thing I need to do and I already don't have extra time or the money to do it. Hopefully you have developed a support system of family and friends who can help you take some time off - even for a walk. It is really worth the creative energy to manufacture time for yourselves, so you have the energy to give to your special needs child and the rest of your family. Remember, if you don't have it you can't give it.

For siblings in the family, arriving in Holland instead of Italy has an impact on them also. Children know something is different about their sibling, even if they cannot tell you. Typically developing children are excellent observers of their surroundings and they notice everyone's reactions to their autistic sibling's behaviors. Some young children wonder if they can "catch autism". At times, they may be resentful of all the time and attention their special needs sibling requires of their parents and may feel they are unfairly treated. At other times, sensing their parent's emotional distress, the child may be unwilling to ask questions, of which they have plenty, so as not to upset their parents. Sometimes siblings can be embarrassed by their autistic brother or sister's behavior and teased about it by peers, fearful of their aggressive outbursts, angry and/or guilty and protective of their special needs sibling. Older siblings may wonder if they will have to be responsible for their special needs sibling after their parents die.

But current research also shows that the majority of children with siblings with autism function well throughout their lifespan; as children, adolescents and adults (Ferraioli, January, 2010). There is some evidence that these children have a more positive self image, greater interpersonal skills and caretaking skills. Some brother and sisters have stated that having a special needs sibling has taught them to be more tolerant and understanding of individual differences. Recent research (University of Oregon 2010, March 8) suggests that older siblings of autistic preschoolers may be at greater risk for fidgetiness and attention problems. They do not know if this is due to genetic risk or a challenging family environment raising a special needs child. They do recommend that these siblings be monitored for any academic or behavioral difficulties. Research has also shown that support groups for siblings who have an autistic brother or sister is beneficial especially when combined with follow up sessions.

With the increase of children being diagnosed with autism spectrum disorder (ASD), many families are navigating the challenges and rewards of raising an autistic child. Hopefully resources will grow with this increased need, so ASD children, their families and siblings can get the support that they need. As has been the case with getting support for children with learning disabilities and ADD/ADHD, this support was started with grass roots efforts of families impacted by these special needs. They formed organizations such as LDA and ChADD, that successfully influenced government regulations, educational regulations, advocacy and research in these areas. There is much research to be done regarding ASD, but it is the families involved with it on a daily basis that know best what kind of support they need. Be a strong advocate for your ASD child, all your children and for yourself. Through local and internet support groups, various websites and developing your own support base through friends and family, your journey through Holland with your family can be just as exciting, stimulating and yes challenging, as a journey through Italy. Remember Emily Perl Kingsley's poem, "If you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland".

Resources:

1. The National Autistic Society, London, England
2. University of Oregon (2010, March 8). Possible early glimpse of autism's impact on older siblings.
3. Social Work in Mental Health, Vol. 8, Issue1, January 2010, Ferraioli, S., Harris, S.

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