



Many of you are familiar with Welcome To Holland, an essay by Emily Kingsley – if not I included a copy as it embodies the life changing feeling of being one of ‘those families.’

I never thought I would be one of ‘those families,’ but I am and I am so lucky. Maggie changed who I am forever. It was not easy and there were many days I was not sure where to turn or what to do and many days I still have no answers. But I think I was one of the lucky ones.

Maggie was born full term and we had no idea that she was not going to be just like her brother. That changed the second she was born and finally after 59 days in the hospital, two eye surgeries, two brain surgeries, open heart surgery and a stomach surgery we were able to bring her home.

My immediate plan was to quit my job and stay home. I did not think there was any other option and most parents do not have an option and it is really hard and really scary. Maggie struggled with eating and was fed thru a g-tube for a significant portion of her feedings, was being fitted for hearing aides and we knew she would need glasses soon. I soon found out I did have options and I learned many years later it was very rare that I had an option.

Maggie’s older brother was enrolled at Kinderberry Hill in Plymouth. The director at the time was named Molly and she had a nursing background. She told me I did have options and Maggie started at Kinderberry Hill when she was six months old. The infant teachers had been my son’s infant teachers three years earlier and they were up for the challenge. They learned how to use the g-tube and they made her feel included. They were like sponges each time I said okay her physical therapist wants us to do this and her occupational therapist wants us to do this and then her speech therapist – yes speech therapy starting at three months - weird I know, but at that point it was more about oral stimulation – seriously it was like earning a medical degree of my own. The point is the teachers embraced the information and assured me it was making them better teachers for all of the children they cared for each and every day.

One of my favorites was when Maggie was starting to finally learn to walk. She had a reverse walker and we carried it back and forth to school each day. Being in an infant room with eight kids there were other kids starting to learn to walk as well. One of her friends watched her and decided he needed to try this thing as well just as his mom walked in to pick him up – it was a story her friend’s mom told for many years after and I loved to hear it every time.

And then it was time to think about the toddler room – I said get another variance and keep her in the infant room. Insert really awesome toddler teacher that said no – she needs to be surrounded by children that will continue to challenge her – please let us try? I was scared as she was not walking yet and how could she possibly make it in a toddler room. Yep, I was wrong – she thrived and soon after was fitted with leg braces and walking on her own.

I could go on for hours, but I want you to know Maggie was so lucky to be included from day one by everyone in our lives. She enriches the life of every single person she meets. Having an early childhood experience was **crucial** to making her the person she is today *and* allowing me to continue in my career. By the way – she ended up as President of Wayzata High School’s Unified Club her senior year and is gainfully employed at Folkstone in Wayzata.

Again, I was lucky. I could afford Kinderberry Hill, many families cannot. I had really good medical insurance. I had access to transportation and early childhood special education through the district. I had a flexible job that allowed me to attend many, many medical appointments and many therapy sessions. I have met so many families that did not have these opportunities. I sit in the stands at Special Olympics events with so many parents that did *not* have options. Some still cry when they tell the stories of trying to find options. In many cases one family member quit their job to be the caregiver as they saw no other way as most providers do not have the ability to provide the extra support for our kids. I have heard countless stories of kids being turned down for childcare options because they needed extra medical support or a little extra patience and the provider just did not have the resources.

You have a chance to change it all. Please provide the extra support that our children need to help make them successful and for our families to succeed as well.

Penny Allen, Medina





WELCOME TO HOLLAND

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 guide books 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 a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. 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....and 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."

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

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