I’m often asked to describe the experience of raising a child with a disability to try to help people who’ve not shared that unique experience to understand it, to imagine 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 you make your wonderful plans. You’re going to see the Coliseum, the Michelangelo David, ride in a gondola in Venice. You may go learn some handy phrases in Italian. It's all very exciting. After nine months of eager anticipation, the day finally arrives. You pack your bags and off you go.

Several hours later, the plane lands. And the flight attendant comes in and says, "Welcome to Holland." "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 a bunch of new guide books. And you’ll learn a whole new language. And you’ll meet a whole new group of people that you would never have met otherwise. It's just a different place. It's a bit slower-paced, a little 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. You even see a Rembrandt.

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, very lovely things about Holland.