



The Gift of Time

The Role of the Community in Youth Transition

By: Eileen Forlenza

My beautiful Holly is a thoughtful and delightful 23-year old young woman who, in spite of her girl-next-door appearance, is not able to feed, dress or bathe herself. She is non-verbal – she has never spoken a word and realistically never will. Since infancy, she has lived with an average of 20-150 seizures every single day. She has partial hearing loss, with cognitive assessments revealing an IQ of roughly 25 – close to that of a two year old child.

Surprises are common in our life with Holly – small steps of independence that we celebrate. However, the constant oversight is exhausting - interrupted sleep is the norm. Holly requires 24/7 care, support and oversight; All day – every day.

Like my husband and I, there are many parents with an adult child who requires 24/7 care who simply need a break. Sleepless nights and constant caregiving can take their toll, with accumulated health and financial stressors can be a lonely journey at times. Finding this kind of respite is challenging as there is no “system” that supports families with community- based care. Her life is no longer attached to public education and is certainly more than the episodic intervention with her medical home team. Exploring, planning, coordinating and implementing are constants and critical for all of us!

Several years ago I brought together a group of families and community agencies to design a community based respite program. The program is now fully developed, and once a month Holly hangs out with her peers for six hours enjoying a deep sense of independence. Just as her siblings have done, she laughs while she looks over her shoulder as I leave the parking lot. I marvel at how fundamentally normal it is for a 20-something to want to spend a Saturday afternoon doing fun stuff without parental oversight. Indeed, it is part of the human experience for a young adult to yearn for independence. I have finally begun to see things differently. One of the hardest lessons I have learned as a parent is to know where I end, and where Holly begins.

Seeing Holly as an emerging adult regardless of her care needs was a huge revelation for me. For me, the once-a-month respite program and its gift of time is more than just time. The respite providers always ask me, “So, what are you

going to do today?” Most times I smile, take a deep breath and say, “I don’t know.” It’s kind of funny, not Ha-Ha funny, but odd funny when you realize that you can do whatever you want for the next several hours. So for one Saturday a month I’m Cinderella. I can go to the magical mall and try on glass Nikes; get a mani-pedi; or just hang out with Prince Charming on the couch.

So the fundamental nature of the gift given by this respite program isn’t solely quantified with a clock. And the reciprocal gift back to the care providers isn’t just logging hours for continuing education. These care providers are learning from the best teachers in the world. They are learning that people with special needs simply need special people to share a Saturday afternoon with them –playing, hiking and laughing.

Eileen Forlenza is a writer, trainer and motivational speaker sharing messages of hope and inspiration to audiences nationwide. Eileen was honored in 2010 as the Woman of the Year from the National Association of Professional Women and also received recognition from President Obama as a result of her advocacy work for children with disabilities. Eileen is an advisor to Got Transition, assuring the parent perspective is embedded in the work of the Center. Eileen, her husband Scott and their four children are dedicated to several community initiative in Littleton, Colorado.