Ben's Transition Story: An Evolving Journey

My middle son, Ben, is the happiest member of our family. Ben loves his life and is actively engaged in our community. Ben, who is 21, holds several part time jobs, loves country music and karaoke singing, is an artist who is currently painting, and works out daily on the treadmill. Ben is funny and loves interacting with people. Ben also has half of his brain, which resulted in a significant developmental disability and no functional use of his right hand and arm, along with vision and hearing loss.

Ben was born with a benign brain tumor that was diagnosed in utero when I was 36 weeks pregnant. He was delivered by C-section at 38 weeks and had perfect Apgar scores. His tumor was set to be removed when he was three days old. However, at one day old, he endured a ten-hour surgery that cut off the blood flow to the tumor prior to surgery so he would not bleed to death. The tumor removal was successful and at three days old, Ben survived another surgery, this one lasting 14 hours. Ben's early days were filled with lots of early intervention from *Birth to Three* therapists and teachers, and lots of hugs and love from his parents and older brother. When Ben was eight months old, he developed Infantile Spasms, a serious seizure disorder that was very difficult to control. After more than a year of trying different medications and interventions, the only real choice that we had left was for Ben to have the remainder of the left hemisphere of his brain removed. This surgery (15 hours, this time) was successful; removing the focal point of Ben's seizures. He has been seizure free since this surgical procedure.

I tell all of this to set the stage for Ben's story. In a sense, we have been helping Ben transition to adult life since the time he was born. Some of the best advice I ever received about being Ben's mom was from his first neurosurgeon, who said "Remember that you will need to work hard to maintain balance in your life. You have a husband, you have another child and you have yourself. Be careful not to focus all of your being on Ben's development."

My husband and I took that advice to heart. In the ensuing years we raised our children, never putting limitations on what Ben could do. We provided Ben with the same opportunities that we offered to our other two sons who have developed typically. And, we always had high expectations for Ben and held firmly to the belief that Ben would not follow any prescribed path of what he should or could do; rather, we let Ben lead the way to show us his interests and abilities. We allowed Ben to define himself, not to let his disability define Ben.

And, it is Ben who, while he was in high school, started leading his IEP meetings. Ben talked about what he could do well, and what challenged him. Ben was the one who, when thinking about a work schedule after he completed school, said that he wanted to sleep in one morning a week and only work four and a half days. Ben is very fortunate to have grown up going to inclusive schools and living in a community that is comprised of individuals who are exceptionally creative, open minded and truly value the abilities of all people.

Ben is always going to need a certain level of support to achieve his dreams and to maximize his abilities. While Ben has increasingly become independent in achieving skills, and will continue to increase his independence, he (like many of us, I imagine) will always need support. This interdependency is not based on a lack of independence; rather, it is reliant on others for mutual interaction, both social and functional. At the core of this interdependence are relationships. Ben has taught me that relationships are essential to asking for and receiving good support.

As Ben has grown up, he has developed many relationships. From the beginning of Ben's life, these connections were based on several basic principles which included:

- Reciprocal respectfulness
- Appreciation of one's skills and challenges
- Willingness to be proactive and creative
- Honesty and frankness when dealing with problems
- Keeping perspective and not getting caught up with little irritations
- Negotiating conflict to find common ground

My hope for Ben as he continues his life journey is what I wish for each of my sons: a life that is fulfilling and interesting, filled with joy and happiness, and whereby each of them continues to inspire those with whom they come into contact.

The Wisconsin Board for People with Developmental Disabilities produced a video on Ben's transition that can be found here: http://www.youtube.com/watch?v=WXqkuZkJ5Xo

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