

A family's journey with cerebral palsy

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By Tina Calabro /

Baby Mark -- nearly 1 year old -- is studying his outstretched hand. The hand moves ever so slightly, more from gravity than intention, and Mark keeps gazing at this strange new object. It's the first time Mark has contemplated his hand with such concentration, so I am watching, too. Absorbed in the sight, suspended in time, wondering what this discovery might mean about my little boy's brain.

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With these words 17 years ago, I invited Post-Gazette readers into my new world as the parent of a child diagnosed with severe cerebral palsy. This week, as Mark graduates from high school, I invite you to meet my son again and to look back on our family's journey.

Much like the mother I was then, I still look at my son with watchful eyes, but now they fall less anxiously upon an extraordinary young man and produce a different kind of wonder -- not only for his personal achievements but also for all who have had a hand in them.

Mark's cerebral palsy -- the umbrella term for conditions resulting from a brain injury that occurs immediately before, during or after birth -- was the result of oxygen loss during a difficult delivery in which my uterus ruptured at the site of a previous Caesarean.

For several hours after birth, Mark breathed by machine. Over the next few days, seizures came, went and -- inexplicably -- never returned. An MRI showed damage to the basal ganglia, the part of the brain that controls movement coordination. Multiple disabilities and complex medical problems were a certainty.

After a month of intensive care, our baby, still frail, came home with me, my husband Dave and our then 5-year-old son, Paul. Because of weak and uncoordinated swallowing, ingesting anything by mouth was not only frustrating for Mark but also dangerous. Within weeks, he needed a feeding tube, which he uses to this day.

In his early years, Mark's motor development lagged far behind, and yet in other ways he flourished. He was bright and responsive. Any small accomplishment -- holding his head up a few seconds longer than the time before -- heartened us, despite its distance from normal expectations.

But such moments were easily eclipsed by reality. "What can he *do*?" a friend asked over the telephone one day, unintentionally stinging me with a reminder of that distance.

It was a simple but profound question. Mark could not then, nor would he ever, be able to do much physically. So how, I asked myself with great anxiety, would he ever find his place in the larger world?

Only the ins and outs of daily life over many years could reveal the counterbalance between the passion for life within our son and his serious impairments. Just as important was the gradual realization that countless people were committed to removing obstacles to his development as a full human being.

Our son in cap and gown was their vision, long before it was ours.

"All of us do not have equal talent, but all of us should have equal opportunity to develop our talents," John F. Kennedy said in a 1963 speech, presaging five decades of national discussion about the inclusion of citizens with any type of difference in mainstream American life. Mark, who grew up amid this discussion, found doors opening that would permit him to reach his potential.

On Saturday, Mark will arrive at the graduation ceremony with all the visible support that has become second nature to him -- custom wheelchair, electronic communication device and a medical backpack. More important, he will arrive with knowledge of William Shakespeare and Frederick Douglass, of Mozart and Michelangelo, of Rachel Carson and Charles Darwin. With a gang of friends he calls his brothers. With plans to attend community college.

Like all graduates, his family will celebrate him not for what he can do, but for who he has become.

Ingredients of support

To raise a child with significant disabilities is to be a perpetual student. Naturally, there is hands-on medical and therapeutic care. Far more challenging are the emotions resulting from chronic sacrifice, relationships in need of attention, the sibling whose life is also affected and simply coming to terms with the medical condition you're up against. Cerebral palsy means brain damage. You can't fix it even though you can mitigate its effects. It is stronger than you.

You also discover, usually by surprise, that you must teach others. The same friend who inquired about Mark's development later asked another pointed question out of concern for my welfare as a caregiver: "How long can you keep this up?"

My friend was thinking about the not-so-distant past when children like Mark were sent to institutions. She wasn't familiar with the changes that began in the 1970s with legal battles to close institutions, ensure appropriate education and support parents so they could raise their children at home.

Thanks to those efforts, Mark was lucky to be born into an enlightened age and society. Mark's civil rights and practical necessities are well defined. As parents, we felt supported to do our job.

Not that the work is ever done, and that's a lesson, too. To raise a child with a disability is to accept advocacy as a way of life and to teach your child to speak out to the best of his or her ability. Parents of children with disabilities often work together to maintain the gains for which our predecessors fought in decades past. The terminology of those groundbreaking accomplishments resound like mantras -- "right to education," "self-determination," "home- and community-based support," "reasonable accommodations."

Set up for success

It is an unending task, this collective advocacy for best practices and adequate funding, but there is no question that our region, state and nation have come a long way as a result.

Because of these efforts, Mark was set up for success. When he first arrived home from the hospital, therapists came into our home to introduce us to the team approach that is the hallmark of high-quality disability services.

As Mark entered preschool and kindergarten, the Pittsburgh school district encouraged us to place him in a regular school, assigned a personal-care assistant and identified the services that would enable him to learn alongside his peers. Thanks to experts in the field of augmentative and alternative communication, Mark communicates effectively even though he cannot speak with his own voice and completes schoolwork without the functional use of his hands.

Mark's main source of motor control is his head. He activates his DynaVox communication device with switches positioned near each temple. Those switches also enable him to drive a battery-powered chair and use a computer. At age 5, Mark taught himself to read by playing around with letters and sounds on a screen. At 10, he learned to compose simple melodies using computer software. At 16, he got an electronic drum machine and formed a band with friends.

Mark's medical needs are complicated, and answers do not exist for every condition. His overall health is fragile. He gets sick more often and more seriously than most people. All of this is frightening for him and for us, but the outstanding medical resources in our region make our path easier to travel.

Mark is also well supported in his transition to adult life. Because he is legally entitled to special education services through age 21, the school district will hold his diploma until he completes its CITY Connections program. Through the program, he'll take classes at Community College of Allegheny County and learn the skills of independent living. Mark will always need a personal aide, but he wants to be as independent as he can.

This transition stage for students with disabilities is much on people's minds these days. Because of a surge of new attention, many young people are feeling more encouraged about their prospects and parents are feeling less fear about the future. Through a Pittsburgh Public Schools initiative called "Start on Success," Mark is already applying his computer skills in a part-time job at the Woodlands Foundation on the Marshall/Bradford Woods border. The Children's Hospital Advisory Network for Guidance and Empowerment is preparing Mark and other teens to take charge of their own health care. United Way's 21 and Able project (which I am involved with as a consultant) is creating pilot programs and policy proposals that will help young adults achieve employment and other goals.

Indeed, over the years of Mark's upbringing, the opportunities for people with disabilities grew along with him. There's still a long way to go, however, to achieve the essential promise: "We hold these truths to be self-evident. That all [people] are created equal."

Problem with superlatives

Please don't tell Mark that he must be a genius like Stephen Hawking, the astrophysicist with amyotrophic lateral sclerosis, just because they both use communication devices. Mark accomplishes more than you might expect, but effort and perseverance are the keys, not amazing mental prowess.

Don't put him on a pedestal, but don't pity him either. The middle ground is good: openness and understanding. Mark lives a complex reality of dependence and independence. He needs help to do many

things, yet he wants to give as well.

The simple signs of acceptance matter most, not the grand gestures. When Mark is in the school hallway and someone calls out, "Hey, Mark," as he rolls by, it speaks to a deeper place than high praise ever could.

Which is not to say that Mark never feels isolated or left out. He does. But he understands that connection requires reaching out from both sides, and he keeps trying.

Seventeen years ago, when I wrote about our "new world" with Mark, I didn't know how disability would merge with the general flow of life -- I just knew it had to. I certainly could not imagine our son speeding through the busy hallways of a typical high school, but he does.

Seasoned disability-rights advocates pointed the way to opportunity and taught us the strategies to get there. As a mother, powerful instincts welled up in me, insisting that Mark would not be denied his dignity or the best that life has to offer. With fatherly, protective love, Dave was ready to crusade for Mark, too.

There's a different kind of grace in the journey that disability takes a person on. The professionals who work with children with special needs -- aides, nurses, therapists and so many others -- allow their connection to evolve well beyond their duties and accept profound feelings in return.

The parents of other children with disabilities are the sisters and brothers with whom we share what is largely unspoken in our daily lives -- hopes and fears, triumphs and losses. We are different people because of our children, sometimes transformed in implausible ways, like finding ourselves able to speak out for our children in a manner we may not ever have had the courage to do for ourselves.

Learning to swim

When Mark was born, I worried about the childhood his older brother would have. Life would no longer be simple. But early on, I saw the seeds of kindness and patience in Paul. Today, he is like so many other young adults who have grown up understanding disability. Studies show that many of these siblings go into helping professions or are more caring people in whatever profession they choose. My heart fills with pride over both my sons.

I now see myself in the younger mothers who watch their special children closely, like the mother who recently posted on a message board about her son's valiant effort in his first martial arts class:

"... My little boy with low muscle tone was trying desperately to do everything that the other kids were doing. My little boy with no attention span was trying so hard to pay attention. [I saw that he is not quite ready] for martial arts, but my heart just about burst because he has come so far."

I have almost stopped watching Mark so intently, something that has become our private joke. "Stop staring?" I ask him when he catches me doing it. He replies with two quick blinks -- which signal "Yes" - and a very patient smile.

Like most parents of children with special needs, we will never be off duty, but we can start letting go. Mark wants us to, and we need to.

Not long ago, the expression "sink or swim" came up in a casual conversation. Mark seized the

opportunity to drive a point home. "Let me swim," he wrote on his screen.

Up to now, Dave and I have made the decisions that shaped our son's life. Now Mark gets to decide.

And his story is *his* to tell, not ours.

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