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UPON GRADUATION

By Mary Ulrich

Parents often have been the instigators of more inclusive learning communities for their children. In the following letter to her son Aaron, a young adult with autism, Mary Ulrich describes the efforts made and the collaboration that occurred in maintaining Aaron in inclusive learning communities.

Dear Aaron,

Today is a special day for both of us. Today you will graduate from high school. In the speeches, they say that the measure of success is not what you achieve but the number of obstacles you nave overcome. The last 22 years have been a journey filled with more than a few obstacles. You are a success, and we are all very proud.

Our culture celebrates this ritual of graduation as a transformational experience from childhood to adulthood, from dependence to independence. But dearest, like everything else in your life, you are rewriting the book on what *childhood, adulthood,* dependence, and *independence* mean. You thought for ail these years that you were the student but in reality you have been the teacher for all who would care to listen and learn. I cannot speak tor you or for others, but I can tell you of my transformational experiences as your mother and co-traveler.

When your dad and I brought you home from the hospital, you had balloons over your crib to help your eye tracking, bells on your wrist, and bright blue booties on your feet to encourage movement. You were nursed, cuddled, exercised, sung to, and loved as the most precious baby on earth. Yet despite the best advice of the Brazeltons, the Whites, and al the other experts of the world, at 9 months of age you could not reach for objects or raise your stomach off the carpet and you cried incessantly. Although the pediatric neurologist could find nothing wrong with you physically, he told us that your mental development was far below typical and that you would always be in special schools. We made a trip to the National Institutes of Health in Rockville, Maryland. We began weekly regimens of occupational and physical therapy. What is ironic is that the speech-language/communication therapy, which is probably what you needed most was never even suggested, because your chart carried the label of *mental retardation.* We tried vitamins, special diets, standing you on your head, swinging you in nets, and reading everything about anything anyone would recommend. It seemed impossible that our precious baby had some mysterious problem that Modem Medicine could not even identify, much less cure. Aaron, you were just so beautiful, so wonderful, we just did not want you

ever to have to suffer anything. Your dad and I wondered what kind of a life you and your new brother. Tommy, would have—would you know any happiness, have any friends, enjoy a camping trip to the mountains, ride a bike, grow to be independent and make a contribution to society?

Even though your dad and I are teachers, we did not have a clue about what the neurologist meant by "special schools." Did he really think we would send you and Tommy to a school that was not "special"? Your dad and I also did not know anything about people with disabilities. In our 25 or so years of living in our neighborhood—going to school, church, the grocery store, and being part of our community—we had never had a single firsthand experience with a person with a significant challenge. We were naive.

We also did not know that a federal law called Education for All Handicapped Children Act of 1975 (PL 94-142) was just being implemented and that this single piece of legislation would be as important to us as the Emancipation Proclamation was to the slaves. This law was the difference between our neurologist's worldview of specialness (i.e., charity and pity for those less fortunate) and a different paradigm based on the philosophy that individuals with disabilities are citizens with the right to an education in the least restrictive environment It seems, dear Aaron, that you could not have picked a better time to be bom.

Your right to an education began at age 5 years. So, almost on your fifth birthday, we filed a lawsuit on your behalf so that you could go to school with your brother, Tommy, and the neighborhood children. Remember Neill Roncker, your friend, who was also in a U.S. Supreme Court suit with our school district over the same issue? It took almost 3 years of battle, but when we won, Aaron, you were the first person with a significant disability to enter the public school system. Large school districts do not like to lose, however, and our school district was not child centered. Besides, we had this little problem that Dad worked for the same school district in which we wanted you to attend school. Fortunately, Dad had tenure, but the specialness paradigm was just too embedded in our community. So, we searched the five-county area around our community and learned that you and your brother could attend the same school if we moved into one specific subdivision in one specific school district After we moved, Dad drove the 20 miles back to the old neighborhood to work each day. It seems outrageous, but such is discrimination. The name of the new school district *Lakota,* derived its name from a Native American word meaning "coming together as one."

On your graduation day 13 years later, the old school district still has segregated schools and classes. Your developmental twins, 21-year-old students with developmental disabilities, are still stacking colored rings while you're working half a day in the local police station as a custodian's assistant and, together with a job coach, half a day in the community with other adults with disabilities. Yea, Aaron!

Not that the new school district or new county board were perfect—not by any means. We certainly had our difficulties. But they grew with us. They made the effort

Remember when the big yellow school bus came to our street and you and Tommy got on together to go to the neighborhood school? No police escort no angry mob—you just sat at the front of the bus and went to school with the other children from our neighborhood. What a moment! After all the lawsuits and numerous meetings with 25 professionals telling us that integration was folly—just by moving to a different district you just got on the bus and rode to school. That was a transformational moment for me. As the bus pulled away, I cried and cried that such a simple event was possible. If our vision was for you to be assimilated into our society, and if the other students were to learn tolerance, then this simple act of inclusion on the bus was a giant step. Later, when the bus drivers formed a union to try to get you off the bus, the director of special education came to the rescue. The bus drivers were trained. Some drivers quit but others became your good buddies. They began to understand that discrimination, whether because of race, religion, or disabilities, is wrong. For the next 13 years, we would run into boys and girts, young women and young men, in the grocery store or at the mall who would come up and say, "Hi, Aaron I" and when asked how they knew you. they would frequently reply, "Aaron rides on my bus," and they would give you a "high five"

There was a wonderful gymnastics teacher who allowed you into the after-school gymnastics class "as long as you didn't take away from the other students." We had to choose

between a physical therapy session and the gym class, and we made the right choice. I was your assistant in the beginning, but later your special education teacher took over. It seems she was a cheerleader and gymnast in high school and really enjoyed getting to know other kids in the school.

This led us to Jessica, a 9-year-old general education student, who observed that when there was music with a steady beat during gym class, you were able to walk easier and faster. Her father, who happened to be the music teacher at our school, was then asked by his daughter at the dinner table to allow you to play in the school band. So, the next week, Jessica not only stopped by your classroom to insist you go to band but also stopped by our house one afternoon and wanted to take you for a walk around the neighborhood. Aaron, you and Jessica made it only about 10 houses down the street, but when you came back, Jessica said, "Aaron is such a good listener. I was telling him all my problems, and he stopped and gave me a hug and said. 'Ahhh.'" Well, there was much celebrating in our house that night and every time thereafter that Jessica came to visit. The fact that you did not talk with words was a plus for Jessica.

Aaron, you and your dad and Tommy went on many Cub Scout and Boy Scout outings. The troop was sponsored first by the elementary school and later by a local church. Andy, Bobby, Todd, and, of course, Tommy figured out ways you could participate in the Klondike Sled Pull; the winter sleepout; and the highlight of the year, summer camp at Woodland Trails. In the middle of the week at each summer camp, the boys were to rise before sunrise, paddle canoes across the lake, and cook breakfast on an island. In order to ride in the canoes, you have to pass the swimming proficiency test. Aaron, you have always been a pretty good swimmer, but it was impossible for you to do all the different strokes for even the beginner's certificate. The scout director knew that you would be wearing a life jacket and that your father and brother would be with you. What they decided was that if you could do some sort of an independent float without a life jacket for 10 minutes, then it would be safe for you to join the canoe trip. The scouts went into action.

They surrounded the deep end of the pool, and you were set adrift Each time you would head toward the pool wall, one of the scouts would "shoo" you back into the deep water. It was probably the longest 10 minutes in Woodland Trails history, but Aaron—with the help of all the other scouts—you passed the swim test. You participated in the canoe trip, and. during the awards ceremony at the end of the week, you received a "Special Beginners" swimming badge to shouts and a standing ovation. That was another transformational moment for me because my old definition of *independent* was replaced with a new concept called *interdependence.* With a few modifications, some accommodations, and a little support, safety rules were upheld and scout laws were not deemed sacred; these boys did not just recite but honored a code that says, "A scout is trustworthy, loyal, helpful, friendly, courteous, kind, obedient cheerful, thrifty, brave, dean, and reverent." Years later, when Todd and Bobby became Eagle Scouts, they talked about how they helped you achieve your swimming badge, and they asked you to light a candle in their court of honor ceremony.

Because many of the same kids were in band and scouts, at the spring chorus recital at the junior high school, instead of wondering why you and your teacher would stand in the front row of the chorus and not sing a word, their parents came up to Tom and me and said, "It's great that Aaron got to sing in the chorus. I noticed that he swayed to the music and one time dapped." The finale was a rendition of "That's What Friends Are For" (Warwick, John, Knight & Wonder, 1985). Indeed! That's what friends are for!

In all your years in school, being on the cross-country team was the seminal experience. Because the Special Olympics track team was practicing at the other end of the playing field, the coach pointed in their direction and, when we declined, asked if Aaron or I were going out for the cross-country team. (I was not since I was obviously not 13 and did not own a purple spandex jogging suit—which all the little 13-year-old girls were wearing.) I thought it was obvious that you were to be the one on the team, and I was to be your support person. There were about a million details for the coach to be concerned with, so he had one of the students lead the warmups. Aaron, you were probably laughing inside as we just joined in the exercises as best we could, because you were in the general education gym class; the rest of the kids were comfortable and hardly noticed you. As we were told to jog around the tennis court the coach watched and then asked.

as we went past, "Can Aaron run?" I remember that I calmly said "No" and kept going. The next practice, the coach called me over and said that he had spoken to the adapted physical education teacher (also the coach of the Special Olympics), and she said not only that Aaron could not run but also that he had to sit down on the floor to cross over from the carpet to the linoleum. I said that was true, and then we just continued on our laps around the tennis courts. Of course, one of our laps was three laps for the other kids, but we got in a routine of encouraging and saying hello by name to all the runners who passed us.

The coach, Mr. Seiple, taught science at the high school and was a lovely person. He just did not want anyone hurt, and he could not imagine why you or I were there. (Plus, I'm sure he got an earful from the adapted physical education teacher.) The wonderful thing about cross-country is that each school has one select team, and everyone else runs in the open division to beat their individual times. Several times, Tommy ran fast enough to be on the select team; but 90% of the time he, Andy, Bobby, Renuka, Elaine, and the majority of the rest of the group ran independently.

Since all of the 13-year-old students needed rides, the parents of the team members in our neighborhood were more than a little thankful that I was willing to drive every day. I loved to look in the back seat and see Aaron squished between three other kids. Gradually, you and I became accepted members of the team.

I remember the offhand questions as the runners would lap us. Renuka once asked why you bit your hand when we went down a hill. She slowed her pace for the answer that Aaron has balance problems and that going down the hill is especially hard for him. "Oh" was her response, and she ran on. Tommy told me that in one race in which he lost his shoe on a tree root and finished the race with one bare foot, when his foot really hurt he remembered how the beat of music helped Aaron. He started singing and that strategy helped him finish the race.

There is a rule in our state that you are not allowed to have a coach or a co-runner. So, our family decided that we would save that fight for another day, and Aaron and Dad ran the prerace practice run. Then Aaron and I would stand at the head of the trail and shout encouragement and the runner's names as they ran past us. It sounded like an old church chant as "Go, Todd!" and "Go, Tommy!" echoed down the sidelines. Because none of the other parents knew the kids' names, this was a contribution that we could make to the cross-country team community. So, Aaron, even though you never ran an official race, we partially participated in everything. You lost 10 pounds, slept better at night and could walk up to 3 miles at a time. You rode the team bus, got a team uniform, and you and Tommy were both in the cross-country team photograph for the yearbook. At the award ceremony, you both got school letters that were proudly worn through all of high school. More than one co-athlete told us that when they would get really tired, they would pass you and be inspired to keep on.

Each happy story is a golden nugget that I keep dose to my heart Your Personal Futures Plan (Mount & Zwemik, 1988), or dream plan, hopes that each day you will get a hug, a song, a tickle, and opportunities to sweat and learn new things. Your dad, your brother, and I hope that you will be surrounded by people who love you—that people will see your gifts, strengths, and talents. We hope you have lots of choices in each activity and varied environments. Now we smile at our earlier concerns because wo know that you can have happiness, friends, camping trips to the mountains, and go for rides on a tandem bicycle and a motorbike. We know that you will be interdependent—a much healthier condition than being independent—and that you will continue to make contributions to society.

Through the last 22 years, your lifetime, our society has gone from legal isolation and segregation, to integration and mainstreaming, to inclusion and full rights and citizenship for persons with disabilities. I have gone through the personal transformations of being oblivious, to being a mother, to being an advocate, to wishing I could be just a regular citizen who cares about all devalued people. I no longer beg tor opportunities to mainstream "if it doesn't bother the others." Now we just assume that you will be allowed to participate. We do not try to "fix" you but rather try to fix the environment with accommodations and adaptations. You are a great kid just the way you are. Working on this new vision, this new worldview, has consumed the years. Because of you, dearest Aaron, I am a differ-

ent person than I might have been. You have been and continue to be an incredible teacher. Perhaps that is your greatest gift and contribution to society.

Today all of the 600 graduates in our district are also making the transformation from childhood to adulthood, from dependence to independence. They are not just more computer literate than their parents, these graduates are starting from a different place with different transformational experiences than their parents. They are not oblivious about people with disabilities. They at least have some reference point, some beginning history. As they are creating their visions of the future, some of those future visions have deep roots in past experiences—experiences from observations and the interactions of their parents, teachers, bus drivers, school administrators, scout leaders, coaches, and peers. Remember Renuka? She is Lakota's class valedictorian and is attending premed school at the University of Virginia. Andy is going to the University of New Mexico and wants to become a priest. Bobby is going into engineering at the University of Cincinnati. Lauren is getting married and wants to start a family. Amanda is in nursing school. Lamont is on a football scholarship at the University of Kentucky. Your brother Tom is going into elementary education at Morehead State in Kentucky.

Aaron, you have touched each of their lives, just as they have touched ours. Their vision and power are interrelated and intertwined with yours. Their future and worldview are also interrelated and intertwined with yours, for they are the next generation of taxpayers, parents, leaders, friends, and neighbors of people with disabilities. For us, school surely means "coming together as one."

Love,

Mom