

# **Inclusion: A Road Worth Taking**

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We watched as the plane was taking off for Maui. The trip was Shawntell's 30th birthday present. As the plane took off from Los Angeles, we started to think back to when Shawn was 7 years old and what has been accomplished over the past 23 years of this journey toward an inclusive life. We also pondered upon what we have learned over this same time period, which may be worth sharing with others. We want to be perfectly upfront with all of the readers: Why go on the journey toward inclusion is not a debatable topic. It is the only way to go even though the journey is difficult, troublesome, and at times challenging.

Inclusion is not something you do just in school or at home. It is not just for some children but not others. It is not for younger children but not high school students. It is not something that happens for "x" number of hours per day or per week. It is how you live your life every day and every minute. Inclusion is a way of living - a way of thinking, believing, planning, and acting.

Twenty-three years ago, people with significant support needs were not even part of the discussion about being included in neighborhood schools and classes. The concept of mainstreaming was focused on children with less significant support needs. Mainstreaming was considered for only those children who were seen as being able to "benefit" from being involved with "regular education students" and the "regular education curriculum." Children with significant support needs were and unfortunately continue in many areas to be educated in self-contained schools and classes. They were not even on the "radar screen" for being considered to be included in the regular education curriculum and with regular education students.

Of course, there were exceptions to this scenario where a few lucky students with significant support needs had their classrooms physically housed in the regular education building, but had a separate school schedule, and a separate bus to pick them up and drop them off at different times, minimizing opportunities for interaction with typical children. Any involvement with typical children was a pure coincidence. In addition, there were examples of students with autism being included in some preschool programs alongside their non-disabled peers, but other students with other types of disabilities being segregated. The landscape was pretty dismal.

Over these past two decades much has changed for children and adults with significant support needs. At the same time, so much has remained the same. There are far more children today who are being included than ever before. There are far more schools and educators who are working and struggling to figure out how to include a specific child in a specific class. This is wonderful. Yet it is a little premature for us to declare victory just yet because too many children continue to reside in segregated classrooms and schools. There are also far too many students who receive their instruction in the regular education classroom, but are not members of the regular education classroom.

Physical presence is important, but not the goal. Inclusion is the goal!

### **Shawntell's Story**

Shawntell started her educational journey the way so many other children with significant support needs at that time used to do, which was to receive services in a self-contained classroom in a church. Shawn received her physical therapy, occupational therapy, speech therapy, and early intervention training from a group of very kind-hearted and concerned educators. She was only two- and-a-half years old at the time.

When we moved to Pennsylvania, we were able to have Shawntell receive her schooling in a self-contained classroom in a regular education school. While there were some interactions with non-disabled students for some parts of the day, for the most part it was children with significant disabilities being in a self-contained classroom. However, we got our first glimpse of what could be accomplished when children with and without disabilities learned together.

When we moved to Kentucky in 1979, we were offered three choices - all self-contained schools. This was not an acceptable option, especially since we had just left a school district which had at least had Shawntell in the regular education building. After some fighting and threatening with the school district, we were able to secure a neighborhood school placement for Shawntell in a special education classroom. While the self-contained classroom was housed in the regular education building and there were many opportunities for typical children to come into the self-contained classroom to help out, the idea of being included in the regular education curriculum was not initially considered.

In 1980, we went to Toronto to attend a conference regarding people with disabilities. Our friend, John O'Brien, had told us about a woman named Marsha Forest who was working to include children with significant support needs in regular education classrooms. While at the conference and stuck in

an elevator, we met Marsha. We talked about inclusion, invited her to Kentucky to spend time with us, and developed our thinking of what was possible.

Initially, we used our new knowledge and insights to help build an inclusive school for our son, Alex. Alex is Shawntell's older brother and is a person with Down syndrome. Using the information we gathered from Marsha as well as thinking these issues through ourselves, we worked with the school district to include several children with moderate support needs to be fully included in an alternative school for children from first grade to high school. The principal believed in the worth of all children and the importance of celebrating diversity. She provided the leadership and stewardship to foster the development of a fully inclusive school for all children. This "experiment" led us to think about how to make this happen for Shawntell, as well.

With Alex being fully included, we turned our attention to Shawntell. While Shawntell was in the regular education school, she was not fully included in the day-to-day fabric of life in the regular education program. However, gradually over time with the support and mentoring of a wonderful teacher and of course fellow students (typical students - and specifically Tanya), Shawntell started spending more and more of her time out of the self-- contained classroom with Tanya - going to classes, and hanging out in the lunchroom, gym, library, and other high-use areas. As time went on, Shawntell stopped spending time in the special education classroom and began spending more and more time in regular education. She got to know more of the kids in the school and started to have other children calling and coming over to the house to play with her after school and on weekends/holidays.

When Shawntell graduated elementary school and went on to middle school she had a wonderful teacher who worked very hard to ensure that she spent her entire day in the regular education classroom alongside her non-disabled peers. While the level of instruction was not what it should have been, Shawntell's relationships and growing friendships with typical children and adolescents continued to grow and develop. Part of the success was because there were children from the elementary school who went on to the same middle school and had known Shawntell. Shawntell spent the next two years in the middle school learning some good things and developing some very wonderful relationships.

We then moved to Colorado in 1986 and had to deal with another school district and our effort to continue our journey for inclusion. We were able to point to the previous educational supports and experiences that Shawntell had and the school district agreed to continue Shawntell being included, first in

middle school and then high school. While the school district never fully embraced the concept of full inclusion for all children, it did allow us to continue Shawntell's educational journey and provided some wonderful teachers and support staff.

Shawntell spent four years at that high school. Overall, it was one of the best experiences in Shawntell's life, especially in her senior year. Over the four years of high school, with the support of an outstanding integration facilitator, Leslie, Shawntell became a true member of the school community. Her friendships and relationships were, as usual, the high point of her school experiences. However, Shawntell also had some outstanding teachers who supported diversity and believed in educational excellence for all children.

After four years of high school, Shawntell graduated and went on to Colorado State University for the next few years, with the support of the local school district, the university, funds from the state educational agency and the Developmental Disabilities Planning Council, and her parents. Shawntell attended classes, lived in her own house with roommates, was involved in the recreational life of a college student, traveled, and continued to develop some great relationships.

In 1994, Shawntell moved to California. Today, she lives in her own house with her housemate of seven years. She has support staff that assists her to be active in the community working, taking classes, and volunteering. She still travels and sees friends from elementary school, high school and college. Life is pretty good - not perfect of course. Shawntell continues on her journey and those of us who care about and love her continue to stand with her to achieve this goal.

## **What We've Learned**

What are the lessons we have learned? After 23 years of working and struggling to build an inclusive life for Shawntell, we have learned the following:

It starts with a dream. The dream must be vibrant, robust, and exciting. The dream must not be easily reached. It must continue to evolve over time. It is about common, ordinary experiences. What we have always wanted for Shawntell was common, ordinary experiences. We wanted her to live in a wonderful home, attend school with all of the children in the neighborhood, have friends, have a social life, move out at age 18 to her own place, have a job and then a career, travel, to have a relationship with God whomever he or she might be, be a good citizen, find love, and enjoy life. These are not

extraordinary experiences, but just common, ordinary experiences that we want for all of our children.

In order to make this happen, it takes a circle of support. While membership in the circle will come and go, it is important to remember that having a circle to get together, discuss, think out, problem-solve, and support one another during the journey is critical. No one can do this work without others standing with them and walking with them.

As our late friend Marsha Forest once said, "Good teachers should teach everyone and bad teachers should sell life insurance." We have had some of the most wonderful teachers over the course of Shawntell's educational journey. Teachers who believed in the worth of each and every learner. Educators who figured out specific instructional strategies to include Shawntell in each and every lesson. At the same time, we have seen teachers who should not be teaching any of our children. When you experience great teaching and great teachers, you realize that all children can learn together and that schools can be places that celebrate and embrace diversity. These schools do become caring communities for all learners.

When we first battled for inclusion, it was based on the issue of social justice. Over the years, we discovered that while social justice is an important concept, it is equally important to fight for quality education for all learners. In the beginning, we settled for presence in the classroom rather than for valued educational outcomes. Over time, we learned that one should not have to sacrifice one for the other. Both are possible and both are important.

First things first. It is important and even critical for quality education to be taking place for all learners. However, the one thing that continues to haunt us and even sadden us has been the lack of true friendships for people with significant support needs. We are not talking about peer tutoring, mentorship programs, best buddies, etc. We are talking about true friendships, especially between children with and without disabilities. As our friend Carol Tashie has said, "If it is so important, why isn't it happening?" To this day,

The most important educational outcome achieved in school has been and will always be Shawntell's friendships.

Person-centered planning is the key. As Alice learned from the Cheshire cat, if you don't know where you are going any road will take you there. It is very important for everyone involved in someone's life to know where they are

headed on their journey and for everyone in the circle to make a commitment to helping the person getting closer to fulfilling their dreams.

Flexibility in the use of resources is important. Whether it is money, time, or people, it is critical to have flexibility in the utilization of all resources. Many of the challenges we faced were about systems and structures being in place that were not flexible and "user friendly."

The journey evolves over time. You start out headed in one direction and then make mid-course corrections. You need to remain flexible and willing to reconsider, rethink, alter, and change the way you are going and what you are doing.

People with significant support needs require outstanding supporters and allies. Without Leslie, Cheryl, Janette, and many others Shawntell would not have experienced life in the way she is currently experiencing it. These wonderful people believed in Shawntell. They believed in the concept of inclusion. They worked each and every day to make it happen. We thank them for what they have done.

Learn to listen. People who don't speak or use any communication system consistently need to be listened to in many different ways. We need to pay attention with all of our senses. When we do, we usually discover that people who don't talk actually communicate the loudest.

When Shawntell was about 10 years old, we told everyone around her to treat her as if she understands everything that people are saying, whether or not she is able to tell us back what she is thinking. The concept of presumed competence is an important one. We just don't know what people are thinking when they have no reliable and consistent communication system. One day maybe Shawntell will have a communication system/method which will allow her to tell us what she is thinking. Until that time, we want everyone to talk to her and act "as if she understands" even though we may not know for sure. This is the "high road" to take on behalf of Shawntell.

When Shawntell was about seven years old, we woke up one morning and decided she wasn't broken. She didn't need to be fixed. She didn't have to earn her way to the "American Dream." This was a very enlightening and important experience for us. When we realized that Shawntell's life was not something to cure, fix, repair, or overcome, we focused on providing the support and assistance that was needed to live a valued life and to get closer to living her dream.

Why do we work, struggle, facilitate, advocate, and everything else? Because Shawntell is a wonderful daughter whom we love very dearly and in order for her to reach the "American Dream" we need to take this road. There is no other way to live if you want to achieve the outcomes we have discussed in this article. The issue has never been whether inclusion is a good idea or a bad one. It is and will always be a way of life for our family. We wish you the best on your journey as well.



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