

THE
Holidays!
FAMILY & COMMUNITY

ONE FAMILY'S STORY OF SWAPPING UNAVOIDABLE CHANGE FOR OPPORTUNITY, TO THE BENEFIT OF THEIR DAUGHTER WITH DEVELOPMENTAL DISABILITIES AND HER PEERS

CHANGE IS THE ONLY CONSTANT

BY RALPH M. KENNEDY

As the founders of a non-profit agency serving adults with severe intellectual and multiple other disabilities, my wife, Tracy, and I realize just how much a few determined people can help make change happen for our loved ones, and how important it is to realize the generosity of this great nation and its citizens in every state in the union.

HOW MARLA CHANGED OUR WORLD

Marla Jane Kennedy (Tracy was told that her name means “bittersweet gift of God”) is the youngest of the three girls that Tracy and I raised and, in Marla’s case, are still raising. Born in 1976, at birth, Marla gave every indication of being another perfect angel. But, at four months of age, the seizures began. We have never

found a definitive answer for their onset or their continuation for 37 years. At first, keeping Marla at home was our only consideration. But soon, these troubling circumstances required us to realistically consider the survival of our family unit, and getting Marla the educational benefits our little family community tried, but failed, to deliver.

Over the years Marla was served in multiple of community settings, including group homes and foster care. It was a very mixed bag and it seemed we were always begging good staff to stay, and advocating to have the not so good staff removed.

At one point, Marla was found wandering along a four-lane highway while her staff allegedly took a one-and-a-half hour shower. Whenever the group home was shut down by the fire marshal for failure to install a required sprinkler system, we tried to bring Marla home. But the demands put on two working parents

could not safely accommodate what Marla required every day. Tracy reached out to the state of Tennessee and was able to get respite care at Clover Bottom Developmental Center outside of Nashville.

My work required me to travel a good bit. Once, when home from work travel, Tracy and I looked at the possibility of placement at the Clover Bottom as a possible solution, at least in the interim, for Marla. Clover Bottom was licensed as an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID), and we were pleasantly surprised to see that the residential arrangements were now cottages and it was secure environment. Marla would be happy and safe.

Still, our concerns for Marla never ceased. There were issues in the Developmental Center as well. We knew how much Marla loved going to school and worried about what activities there might be to fill that void when she “aged out” of the school system. Then, in late-1995, more change happened.

A FEDERAL LAWSUIT: ULTIMATELY, THE CATALYST FOR A BETTER WORLD FOR MARLA

In 1992, a federal lawsuit had been brought against Arlington Developmental Center, located outside of Memphis. In December of 1995, the US Department of Justice (DOJ) took action against the remaining three Developmental Centers in Tennessee, including Marla’s Clover Bottom. Our world was turned upside down. At the time, Tracy and I had just recently been installed as members of the Board of Directors of the Parent/Guardian Association at our Center.

Little did we realize just how much our lives would be affected in a good way by what seemed like a disaster at the time.

I am a biomedical engineer by training. I had earned a Master’s Degree in Business

Administration in 1995, completing my studies not long before the advent of the lawsuits. The parties in the three lawsuits and the federal court decided to combine the three lawsuits for the purpose of negotiating a Settlement Agreement. There were 1,300 identified class members in this combined class action lawsuit, including our Marla.

Over the spring and summer of 1996, I attended court proceedings with Wanda and Elizabeth, two other members of the Clover Bottom Parent/Guardian Association. Though we did not have party standing in the lawsuit at the time, someone had recognized us as stakeholders and invited us to participate in the negotiations.

The final outcome was a Settlement Agreement that essentially proposed to depopulate the three Centers. The families at the three Centers did all we could to mitigate what I realized was the intended closure of the Centers. We organized a press conference at the state legislature. We mounted a concerted effort to have the matter studied by the legislature and reached out to our federal elected officials in an effort to assure a safety net for those who were the most severely disabled and whose homes were closing. At the time, I felt like I was on board a runaway train. The total ICF/IID bed participation in the

state was reduced from nearly 2,500 beds to 668. Over the next two years, approximately one-half of the 1,300 class members, in what came to be known as the “Clover Bottom lawsuit”, were moved into “less-restrictive” Home and Community Based settings. Yet, lives were not improved as promised. The state’s own statistics revealed that there were now four times the instances of sub-

stantiated abuse and neglect occurring among the 700- plus class members now in community settings over those who remained in the Centers. The collateral damage being done by this process was brought to the attention of the Centers for Medicaid and Medicare Services (CMS) by concerned families. In response, CMS imposed a moratorium on the implementation of the Tennessee Home and

Community Based Waiver. Tennessee could continue to move individuals into community settings but would have to do so without the assistance of federal matching funds. In Tennessee, this amounted to about \$0.66 of every dollar spent on HCBS services. Movement from the Centers was reduced to a trickle.

These were very dark and difficult times for the State of Tennessee and those families caught in the cross hairs of the federal lawsuits against the State developmental centers. It was equally a dark time for many on the State Waiting List as the lack of federal matching funds reduced the state’s ability to take individuals into services from the Wait List. Truly the state of Tennessee was on the horns of a dilemma caught between two federal agencies (DOJ & CMS) with competing demands.

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FAMILIES TAKE CHARGE AND OFFER A SOLUTION

It was about this time that I came up with the zany idea of starting a non-profit agency. My unconditionally supportive wife supported me in this decision. Without her support, I would not have thrown away a promising career in corporate America to launch into something I had nothing but academic preparation to do. We were determined to offer a solution to other parents at the Center where our daughter resided. Many of them were terrified of the future and many continued to be in denial that closure of the Center was even being considered by the state. We also wanted to offer a solution to the State of Tennessee. After all, in our hour of need,

BUSINESS PLAN, RECRUITING FAMILIES, BUYING OR BUILDING HOMES ALL HAD TO BE DONE. I KNEW ENOUGH OF WHAT I WAS GETTING INTO TO KNOW THERE WAS A LOT I DID NOT KNOW.

TENNESSEE FAMILY SOLUTIONS, INC.



The mission of Tennessee Family Solutions is to help people with severe developmental disabilities lead safe, stable and personally fulfilling lifestyles in Tennessee communities.

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EMBRACING CHANGE Ralph and Tracy Kennedy with their three girls.

the State had been there for us and allowed us to live at least somewhat “normal” lives.

What could we do that would be any different from what we had seen others doing?

There would have been very little that we had not already experienced as parents in services our daughter had received. In our searching, we discovered a model of care that had been developed by faculty at the University of Kansas in the late 1960’s. It was called the Teaching Family Model (TFM). It was originally designed to serve troubled youth but some member agencies of the International Teaching Family Association had modified the TFM to serve people with disabilities. So, in the spring of 1999, four members of our Parent/Guardian Association traveled to Kansas to look at the Teaching Family Model.

What Tracy and I found appealing in TFM was that, by design, it incorporated answers to many of the deficiencies we had identified over the years in our experience of community care for Marla. We determined to bring TFM to Tennessee. The preparatory work started.

Business plan, recruiting families, buying or building homes all had to be done. I knew enough of what I was getting into to know there was a lot I did not know. I knew that mistakes could shipwreck an agency in a business that was so heavily regulated by the government. I negotiated contracts with a consultant and set about trying to sell our “solution” to the State and families. Strangely, the state did not want our help. It seems a cottage industry of community providers had developed across the country in the wake of many DOJ lawsuits. The state had recruited new per-

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rewarding at the same time. In 2009, the State of Tennessee announced the closure of Clover Bottom. There were about 100 individuals left on campus at the time of the announcement. Many of them came to TFS.

CONCLUSION: CHANGE IS NOT THE ENEMY BUT OPPORTUNITY

While we as families were adapting to change, the State was also learning. In 2004, Tennessee announced that they would be expanding the number of ICF/IID beds. TFS applied and was awarded 16 of the 76 beds ultimately licensed by the state. There were many difficult times and the opposition came from multiple sources. At times I felt like Nehemiah rebuilding the walls of Jerusalem with a sword in one hand and a trowel in the other. But building or fighting the outcome have been good. Change is not an enemy. Hidden within the change coming at you in life is an opportunity. Your challenge is to find it. •

ABOUT THE AUTHOR:

Ralph M. Kennedy is Marla’s Dad and the Executive Director of Tennessee Family Solutions

sonnel to oversee the development of the new HCBS Waiver system of services. They recruited primarily for-profit providers to the state who had no desire to compete with a non-profit family oriented provider. Fortunately, one Tennessee official embraced our mission and that was enough to secure the start-up funding we needed

I remember hearing, somewhere in my education, that nothing worth doing is likely going to be easy. This certainly applied to the creation of Tennessee Family Solutions (TFS). We opened our first home in the spring of 2001. One small miracle after another enabled us to open homes, hire staff and fill them. Over the years we have taken a number of persons from Clover Bottom into services. We operate in two Middle Tennessee Counties and three different cities. TFM has turned out to be everything we hoped it would be. Unlike other means of accreditation in our field, TFM looks at more than paper compliance. It looks at whether the individual being served has a life.

In 2002, Marla left Clover Bottom and moved into her new home in the Nashville area. I have to say that through all the struggles, I find satisfaction in knowing that we families are in control of the services our children receive. I never imagined anything could be so difficult and yet so