

# That Which Binds Us: Friendships as a Safe Harbour in a Storm

*Jeffrey L. & Cindy Strully*

## **Overview**

For the last ten years, we have worked hard to facilitate friendships for our daughter. We have come to understand that it is friendship, not skills or competencies or even quality services that is most important in her life. We have come to realise that friendships are neither easy to achieve for anyone nor is there an exact path which to follow on one's journey toward inclusiveness.

However, it is friendships that make life worth living. Facilitating friendships for our daughter requires intentionality. Friendships are not going to be achieved unless people purposefully work on forming these relationships. This issue raises many questions for which there are no easy answers. However, unless we take the time to start asking these questions and attempt to determine why friendships happen and what we can learn from friendships, we will never learn how to be better at facilitating friendships for people with the label of developmental disabilities.

As noted, friendships do not just happen. They require hard work. Friendships also force families, integration facilitators, focal people (persons with labels) and their friends to live with tension. Friendships for our daughter have been a series of peaks and valleys. When friends do not want to go out with her or they want to change their plans or whatever, she must live with this. Intentionally asking friends to do things potentially places a strain on the friendships. It may move from being freely given to fulfilling an obligation. These are often very delicate situations that need to be addressed.

Friendships come and go. They are difficult to maintain and even more difficult to describe to people. However, one knows what friendship is really about when one sees it happen and then one comes to believe that it was worth all of the work that was required to make it happen. Shawntell, our daughter, can live without many things in her life (e.g. learning to feed herself, learning to use the bathroom independently, etc.) but she cannot live without friendships. For years, we spent our time teaching Shawntell or working on her physical, occupational or speech therapy goals. Though learning is important to each of us, there was a subtle implication that Shawntell was a broken person who had to be fixed. If she learned the things we were teaching her then somehow her quality of life would

be improved. What we learned over time was that Shawntell was not broken and therefore did not require fixing.

Working on friendship places us under the constant strain of attempting to reach for something, which cannot be guaranteed. However, it is friendships over skills, money, and power and control that make life worth living.

What has not been discussed is the pain and frustration that exists when people start working on friendship. Though friendships are important, even critical to our daughter's life, we would be living in a dream to deny that there has not been pain and frustration in facilitating Shawntell's friendships over the years.

However, though there is frustration and pain in facilitating and working on friendship it is well worth the effort because there are no other real options. It is friendship that will ultimately mean life or death for our daughter. It is her and our only hope for a desirable future and protection from victimisation.

Families and the human service system (Including the educational system) have spent all of their time training, teaching, working with, and habilitating people with developmental disabilities. When one spends time with adults with the label of developmental disability it is easy to see that their lives generally lack true quality. Being a client in a System, even a good System, is nothing to brag about. People are still living in poverty, have limited control, have few if any relationships, staff come and go in their lives and life is a series of programs and learning sessions geared to function better to enable them to become valued individuals in our society.

This chapter is about what we have learned over ten years of working on friendship the beauty and excitement, along with the pain and anguish. It is about learning from doing and then learning some more. It is about working on something that is well worth working and learning about. It is about friendship.

### **A new beginning**

The journey of our daughter's life is about to take a new direction as she begins college as an incoming freshman this fall. Starting college is an exciting time in an eighteen-year-olds life. This is the beginning of a new set of challenges and experiences. There will be new people to meet and friendships to form. Leaving home is difficult for any young person; it is simultaneously scary and exciting. No matter what happens in the future, those of us who care about and love Shawntell are all going to continue to dream about desirable futures and together maybe those dreams will come true.

The journey toward inclusiveness begins when people recognize what is worth working on and what will lead in the wrong direction. For us, getting Shawntell to

just be a regular high school student who was learning all that she could, having fun, hanging out, being with people who cared about her because they were her friends, was and still is what we believe is at the heart of the matter. It is about being welcome and invited in. It's about hospitality and circles of friends. It's about not being the 'stranger, on the outside but being a 'regular'.

As Shawntell's high school days come to a close, it is time to reflect on what that experience has taught us. Shawntell moved to Littleton, Colorado from Louisville Kentucky in 1986. In her first year in Colorado she was in middle school and even though she was in regular education classes in her neighbourhood school things were far from perfect. However, we knew what the gold ring looked like and we were not going to give up until we achieved it! Knowing what is worth working on and spending your time on is critical. You need to determine of all the things that you can spend your time on is this one that will really matter. For our family, we have been able to answer that question in the affirmative. Friendships for Shawntell are the single most important thing in her life.

Over the past four years, Shawntell travelled the road in high school finally attaining the status of graduating senior. The classes that she enjoyed the most were French, American Literature, Music Appreciation, Economics, Science Fiction, and Adult Issues. She has enjoyed being in the drama club, Amnesty International, on the yearbook staff and involved with the Wild Warrior Women - an exclusive club with exclusive membership of only female seniors.

Shawntell has enjoyed spending weekends in Steamboat Springs or travelling to California, Chicago or Florida with her friends! As long as she is with Joyce, Denise, Brandi, Cyndi, and Ruth she is happy. The girls plan things to do (e.g. going to the movies, to a concert, shopping or just weekends where they cook dinner together choose a video to watch and talk late into the night). The girls have come to recognize that Shawntell is the social glue that binds them. This is not just for Shawntell but they rely on each other in order to 'make it' at school. In their daily lives each of Shawntell's friends' care about her and they have learned to care about each other.

For all teenagers the desire to belong and fit in is paramount. The girls speak openly about feelings of alienation and being lonely amongst many people. They search for connectedness. Although academic achievement is important, it is the feeling of belonging to a group that is critical to make it not only at the High School, but also in our world today.

**Knowing where you are going is important.** For many years we journeyed down a road that we believed was the right one. It was supposed to be the one that would help her the most and of course, we wanted to help increase her skill

mastery. For years, Shawntell worked on physical therapy exercises to achieve new milestones. We listened to every professional; we read every book; we attended every conference, seminar and parent meeting. But one day we realised that all of this focused on Shawntell's labels which caused everyone to see her only as a litany of deficiencies. As parents we didn't see her this way. Few saw her as a gifted person. Although helping Shawntell learn new things will always be important this Path of deficiency labels was leading us toward a future filled with human services, paid caregivers, segregation, and isolation.

The dream Shawntell and we have is to have a life of rich experiences, being in the middle of things with her friends. We envision a series of different futures. Among the ones we see are living in her own place with people she wants to live with; learning things that are important and useful but also fun; doing new things with new people; having close and meaningful friendships and relationships. This is what quality of life is all about for Shawntell. Oddly enough for those amongst us that see only her deficiencies these dreams are undeniably what they see as a good quality of life for themselves too. We don't see a future of congregate care residentially or vocationally. We continue to explore different possibilities and take new paths while enjoying a meaningful life.

Shawntell has started college this year like millions of 18 year olds across the nation. This is the beginning of her journey to adulthood. College is where many people are practising interdependence, emancipation and self-reliance. College is a place Shawntell can take four years to try and figure out what she wants to do with her life. Shawntell does not need transitional living she needs to become her own person.

We don't know where this journey will lead Shawntell. There are no annual goals and measurable objectives any longer. Life is a mystery worth living. As long as Shawntell has love, friends, caring, opportunities, choices, control and power in her life the journey will be a good one. Without these variables, life would look very bleak indeed.

### **Can the system help us**

Shawntell doesn't need a case-manager nor does she need to be a client in the system: she does need require support and assistance to live the good life and develop relationships with others. Being part of life does not mean that she should be part of the human service system. We have worked hard to keep Shawntell out of the system at this time; whether this is possible over time remains unknown. It would be in Shawntell's best interest to have control over her money and the decisions that affect her life rather than being thought of as a client who generates revenue and expenses for a vendor providing service and is managed by staff.

What we have currently is a real dilemma. Shawntell definitely requires supports. She needs to have people around her who are paid to introduce and connect her to her neighbours, classmates, etc. She needs other people to provide day to day support that her friends cannot be expected to assume on a daily basis.

What is required to provide Shawntell the various supports she needs is financial control. Shawntell needs to have the power to make decisions. She needs to have a genuine say over where she goes on her journey. This causes a dilemma between the system and Shawntell with the system demanding that Shawntell alter her journey to conform to the system's needs and requirements and Shawntell demanding her unique journey to be respected and assisted. If real control is provided to Shawntell then the system will be required to rethink and refocus where people spend their time and what they do. What will be discovered is that the system will need to spend its time connecting people rather than teaching tricks. The system can help people become part of the community rather than apart from the community. The System has potential when the power is given to the person with the 'label' and or his/her family.

### **So what we have learned so far**

We have learned over the past eighteen years of Shawntell's journey:

- the journey starts with a dream
- desirable futures are possible
- friendships are at the heart of any future
- friendships can and should be nurtured and supported
- circles of friendships benefit everyone involved in the circle
- having needs does not require a formalised system's response
- having control and power over one's own life is critical
- having opportunities to try and explore new paths on one's journey is paramount
- new paradigms need to be thought about for people and the old paradigms doesn't help bring people into community
- the journey toward inclusiveness is not like road map, it is an adventure to be lived
- Shawntell's journey is not the journey others should follow. Each journey is unique to the traveller
- There is a need for paid and unpaid relationships to facilitate the journey
- there are times on the journey that will cause a need to rethink, change, or modify the path

### **From school to adulthood: lessons learned**

The experiences children and young adults have had in the school system will bring very different expectations to adult services than what adult services are ready to provide.

Young adults and their families are expecting the adult service system to rethink where it spends its time and energy. The system will be expected to help foster and maintain relationships and friendships that were developed in high school as young people exit the school system: at the same time the System will need to support and foster new relationships.

For some learning what has been successful with the school-age population and applying it to the adult service world has been difficult. This may be due to the fact that children have a common place - school and adults don't. This doesn't mean that adults don't spend time in many different common areas such as the work place, community college, figure and fitness salon, the ball field, or the local restaurant, etc. Adults do have common places to be with each other but they look a lot different than school. Another issue that some of us have failed to learn from facilitating friendship for children is the mistaken belief that adults don't need to have someone assist with connections. The assumption that "I can do it by myself" has caused many adults with labels to continue to be disconnected in their communities. Adults with and without disabilities need people to help introduce them to others.

Throughout life there are a variety of excuses that people hold on why establishing friendships cannot happen. Often, we hear that adults (without labels) have careers, family, their own social networks to manage, etc. and because of these demands, adults with developmental disabilities will have more difficult time being connected. There are many people in our communities who do want to know people. If people really have the opportunity to meet and be introduced to people with developmental disabilities, they could find their connectedness through each other.

It is in adult support workers best interest to spend time getting people known in their community and helping people to connect with one another. This requires intentionality to occur.

Without intentionality relationships for Shawntell would never have become a reality. It is difficult for some people to accept that the facilitation of relationships requires purposeful involvement in people's lives. It requires a third party, at least in Shawntell's life, to help to introduce her to others, invite other people to get to know Shawntell, to find places that people can get linked with Shawntell and other strategies to help build bonds of friendship between people. Before

relationships can really start developing people still need to be amongst each other.

A person still has to be present in other people's lives in order for people to come and get to know them. There is a need to be highly visible and in the middle of things in order to be noticed. Whether you are talking about adults or school age individuals, facilitation is required.

### **The Integration Facilitator**

In order for people to come to know other people it may require a third person. The Integration Facilitator becomes the person to introduce and tell a person's story to others (see Forest and Snow, Strully and Strully). Additional activities of the Facilitator are to interpret to others, to make introductions, to find opportunities and to represent the person as if he/she was that person.

When we began to think about friendships for Shawntell in secondary school, it became obvious there was a difference between elementary and secondary school in terms of parental involvement. In elementary school it is acceptable and even advisable for a parent to be actively involved; however, in middle school this changes and parents aren't as involved because children are learning to become independent from their families. At this stage, it was obvious that Shawntell needed to have someone from the outside devote their attention and efforts to facilitate these friendships. When Shawntell began attending High School, though things moved in a positive direction, the 'teacher' assigned to facilitate for Shawntell was also responsible for other students with complex needs. Although this teacher assisted with the facilitation of several relationships, she was unable to devote the attention that was needed to take these relationships to a plane beyond just caregiving. These relationships were not of the quality and intensity that we felt Shawntell needed. The relationships were fairly superficial and basically at a caregiving level not ones based on mutuality.

When the next school year began, we decided that were running out of time before Shawntell aged out of the school system so we decided to hire an integration facilitator that would be solely responsible for Shawntell. After we hired this facilitator, the Colorado Department of Education and our local school district decided to become more involved in this effort.

Leslie fulfilled the role of facilitator for a little over two years. What made Leslie an excellent facilitator is that she is in love with Shawntell. We feel that this is a key factor for a facilitator to have. She is committed to Shawntell and understood and experienced what life is like through Shawntell's eyes.



Living in our society where people can't see you, but only your disability, is very troublesome and Leslie felt that pain of isolation that Shawntell had experienced. Leslie has been the missing ingredient in trying to build friendship in Shawntell's life since she entered the world of secondary education.

Leslie's role has been to bring people together around Shawntell and form a 'Circle.' When searching for friendship, one needs to meet many people before the friends are found. Many people have approached and became involved with Shawntell only to move on after a short time when the newness or uniqueness wears off. Others stayed past the initial stages of friendship. They learned that being a true friend to Shawntell requires being committed through thick and thin. Those people who really are committed are not many in numbers but do exist and more importantly, they are true friends.

Sometimes commitment is not enough, sometimes personal circumstances impact people's ability to remain involved - college, parental issues, moving, work, etc. all create variables that are beyond anyone's control. People who have cared about Shawntell and became her friend and Shawntell theirs have left. This too is a part of understanding friendship, relationships, and the difficulty of being part of another's life.

The summer after Shawntell graduated High School a new Integration Facilitator was hired. Angie is the same age as Shawntell (actually Shawntell is 4 days older) and is new in Shawntell's life. It will take some time for them to get to know each other. In the short time Angie has been involved with Shawntell, Shawntell's social life has improved by the frequency that her social calendar is getting filled up. Shawntell is involved in different types of young adult activities than previously. Shawntell is developing new friendships while maintaining and enhancing her old relationships.

Being an integration facilitator provides many challenges especially when there is a need for Angie to give up her own individuality to allow her to see things from Shawntell's perspective. At the same time, Angie has the very same need as Shawntell a need to be connected to a group of friends. Both girls are searching for a sense of belonging and acceptance in their lives.

Though Angie and Shawntell have experienced many positive interactions at Colorado State University, there is so much to do. There is perhaps an unreasonable expectation on Angie (or anyone who assumes the role of integration facilitator) to fill the void that exists within Shawntell's life. That causes those who care about Shawntell pain and disappointment to be unable to fill the loneliness that exists for Shawntell. All we can do is continue on our mutually held dream.



The Integration Facilitator's role is not easy. There are many demands and pressures upon anyone who assumes this role. Without having an integration facilitator in Shawntell's life many positive developments would never have happened. As we have shared previously, without intentionality and the integration facilitator in Shawntell's life, nothing would have been developed. This raises many questions such as can and should everyone have a facilitator; who should be a facilitator; what happens if there isn't a facilitator available? What can be done, by whom?

### **Pain and Frustration**

Pain, frustration and anger are also emotions that we have felt. Being involved with the facilitation of friendship for Shawntell is not always one glorious celebration after another. There are times in which it hurts. There is pain when we see things not happening for Shawntell; when people are either not aware of what they are doing or don't understand the extent that society holds disability in a negative fashion in our country. Being disabled in America still places people at the lowest rung of the ladder. People's view of those who have been labelled has been conditioned by what they have seen, grown up listening to and the lack of daily interactions with people. Overall, people in our country are still at the 'there by the grace of god' belief system.

People do not recognize the extent to which disability has impacted our schools, neighbourhoods and communities. People's lack of awareness, knowledge and at times understanding is profound. With all of the positive relationships that Shawntell has had over the years, she remains a person with deep loneliness. Shawntell is patient with people who are trying to get to know her, her communication system, her dreams and fears, her desires and wishes. Many people come into Shawntell's life not realising how hard her life is. Most of these people are not able to remain involved with Shawntell because it is hard 'walking in her shoes.'

As Shawntell's parents, we recognize the ingrained nature of prejudice that Shawntell faces daily in her struggle to be free. At every bend, there are professionals and human service organizations wanting to implement some sort of activity, program or service that will distance Shawntell even more from the community, or someone enters her life and then looks for ways to escape so that he/she doesn't have to think or feel what it must be like to be Shawntell on a daily basis.

It is because of this deep loneliness that we have worked so hard to build relationships and friendships for Shawntell. When things are going well, we feel hope this will be some sort of safeguard for Shawntell. It is our firm belief that

friendships can provide one primary safeguard in her life. We know that Shawntell's network of friends' care about her very much. However, even they do not really understand the sense of urgency that we feel as we search for people who will stay around for a while.

The realisation that Shawntell's life is far richer because of her friends than the vast majority of people with disabilities in our country is profound. What must life be if you really have no one! Knowing Shawntell's life is richer makes us feel good that we are working in the right direction, but knowing how fragile her friendships are makes us constantly anxious as we wait for something to happen.

If these feelings are even close to being accurate, then it is easy to understand the sense of urgency that families with adult sons and daughters must feel as they know that there are few if any people who just want to be around their children because they care about them. Hence, the parents place all of their eggs in the human service basket hoping that at a minimum their adult children will at least not be harmed. When families feel good that their adult children are not being harmed, then we know that we must rethink what we are doing and how we are doing it.

The pain and anguish of friendship is not always as obvious and blatant as we have described. Sometimes, it is in little things that take place on a daily basis. Shawntell is being left out of a party or a concert. Shawntell waiting around for someone to call her knowing that she will always be there at the last minute. This part of Shawntell's life is difficult for us. We want so much for Shawntell to be active and engaged all of the time. Accepting the three or four times a week that Shawntell gets out to be with friends is both wonderful and at the same time disappointing. We want so much more for Shawntell, but accept with appreciation what Shawntell has.

Over the last ten years or so, we have done everything in our power to try to increase the opportunities for Shawntell to get to know people, for people to feel welcome at our home, to do the little things that will get Shawntell the chance to be with others. These efforts have paid off, but at the same time it has felt that we have had to bite our tongue from time to time accepting less than what we had envisioned for our daughter. Knowing when to ask, how often to ask, when to let things slide by, how frequently, quality versus quantity arguments, and lots of other issues continue to be raised dally.

It is important to recognize that in her own way Shawntell senses what is happening to her. She knows what she would like to do (go out every night and be with people who care about her), but it is almost as if she knows that will never be, so she accepts the opportunities that do come by and enjoys them.

She doesn't understand when people don't come by as often even though they may have a good excuse. She doesn't understand why if I went out last night I can't go out tonight.

Before this sounds as depressing as it feels, we want to reiterate that Shawntell's life is good. It can be better and we will work to make it better. However, with all of the fan-fare on friendships and relationships these days, it seems that there needs to be at least an understanding of what the 'other side' feels like. Why is it that we work so hard on friendship at the cost of everything else (such as helping Shawntell learn a specific skill or competency) the reason is simple. Without friendships in Shawntell's life gaining additional skills and competencies are useless. Working on making Shawntell's functioning increase is an insult on who she is and what is important. Shawntell will be at increased risk of abuse, neglect and exploitation without friends and relationships in her life. She will never have had a chance to go for the gold ring if we do not work to facilitate friendships and relationships for her. At least we are going to try and go for the gold knowing that our efforts are leading us in the right direction.

### **Final say so**

As we write this chapter a situation took place that clearly frames the issue on why friendship is so critical in Shawntell's life as well as in all of our lives.

Shawntell was eating dinner out with three of her friends. We received a call from Cyndi informing us that Shawntell was choking and that the paramedics were called. We rushed over to the restaurant to learn that not only had Shawntell choked, but that she had gone into a grand mal seizure. As Shawntell was coming out of the seizure and was being transferred to the hospital, her friends forgot about needing to be home by a certain time to do homework, chores, or whatever else. All they could focus in on was getting to the hospital to be with Shawntell. Two of the girls (Denise and Cyndi) had gone together and Joyce had gone with one of us. Denise and Cyndi were in an automobile accident (they were not hurt). We received the call about the accident as the three of us were with Shawntell in the emergency room. Joyce never left Shawntell's side. Joyce talked with Shawntell and made sure that Shawntell knew that she was right there. Joyce defended Shawntell when the nurse was asking foolish questions about Shawntell's functioning level. Cyndi and Denise were lucky not to be hurt in the accident, but when you think about the reason for their impatience with red lights, the speed of other cars, etc. you realise that all they wanted to do was get to the hospital. That's a true friend!

That evening and the following few days were difficult for all of us. However, if we ever become depressed again about Shawntell's life, and we may, we will

never forget the way Shawntell's friends rallied around her that evening. Their caring and concern for their friend in a time of need says it all. Why is friendship so important in our lives? Because none of us should ever be in a hospital (or any other place) without people around us who truly want to be there for no other reason than they care and love us.

We asked Shawntell's friends to have the last word so here are their thoughts:

**Brandy** "I have always had friends in school, but I never really did anything with them outside of school and now we are starting to do things together and now my life is richer"

**Ruth** "Shawntell made it through high school. She will do OK at CSU. It won't be easy but we will help her"

**Joyce** "Times are changing, why aren't you?"

**Denise** "Shawn has helped me to look deeper into myself. Before I met Shawn I was a physically handicapped person striving to be a 'normal' person, because of my friendship with Shawn I am able to accept myself for who I am"

**Cyndi** "Shawn's friendship is wonderful addition to my life. Shawn accepts me as I am and I do the same with her"

As Shawntell's parents, we are excited about our daughter's journey toward inclusiveness. It is her friendships that will provide her a safe harbour in her journey. It is our belief that together we will work to make our communities more caring and accepting for all people. There are only two reasons that you work on any of these things - BECAUSE IT IS TIME AND BECAUSE IT IS RIGHT! We hope that your journey will be as exciting as ours has been. As long as you keep your eye on the prize and keep dreaming, you can't go wrong! Good luck in your search for inclusiveness for yourself as well as the people who you love!

This article is dedicated to Leslie New without whose assistance our daughter would still be a 'stranger' Thank you with all our love!



This information is made available by Family Advocacy and cannot be used except for the sole purpose of research and study. [www.family-advocacy.com](http://www.family-advocacy.com)