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Abstract

This article describes a river trip for 3 adults and 9 teenagers, one of whom - Wilson - has a disability. It compares the positive ways Wilson's needs were met in the context of a family as opposed to the negative way the needs of a group of people with disabilities were met by their service providers. It raises issues about attitudes and perceptions we hold and the importance of recognising people with disabilities as individuals. The article concludes with "...take risks, ride the river and build opportunities for children and families and adults with disabilities".

Keyword: Inclusion

TAKE RISKS, RIDE THE RIVER

By Barbara Buswell

This is the keynote address give by TASH Executive Board Member Barbara Buswell at the 1991 Conference in Washington D.C.

It is a privilege to speak to this group of committed, principled people. Many of you have been mentors to my husband and me.

First of all I'm going to describe the kinds of services and support options that we'd like to see to support our son and our family. And then, since I'm a new Executive Board member, I'll share a few reflections about my perceptions about how this organisation can support families and people with disabilities.

To start out however, I'm going to share with you an experience our family had last summer.

Last June our family took a river trip to Utah for seven days. Since we live in the West, taking a river trip isn't a very exceptional experience because a lot of families in the West take rafting trips. But there were a few exceptional parts to our trip, and the most unusual part is that there were three grown ups and nine teenagers on this trip.

We planned this trip ourselves since my husband Mark is quite experienced at rafting. As with all trips this adventure was a lot of work. One of the very first challenges of the trip was orchestrating the teenagers and getting them up in the morning! After we awakened the kids, cooking for 14 people was quite a challenge. In addition, we learned to do the daily chores that happen in the wilderness. The next challenge was to pack everything that we had used and load the rafts again so we could set out for the day.

The first day we had planned to leave at 9.00, and we got on the river at 1.00 because orchestrating the kids proved to be a much greater challenge than we ever imagined. As we set out down the river, we proceeded in a caravan with our four rafts and two kayaks. We enjoyed the sun, had water fights, battled the wind, supported the kids with interactions when they got too tired to paddle and when they were tired of sitting in the same raft with each other.

At day's end, we dragged everything off the rafts and set up for dinner. We learned to prepare all kinds of delicacies. We learned to do bathing and hygiene in the wilderness, escape from the bugs, deal with sunburn and also found some way to be away from the group and find a little peace. The kids really enjoyed the evening and explored the canyon, found snakes and even created some plays in which they acted. After dinner was a time to sit around the fire, have some time to reflect, get away from people, build sandcastles, talk and dream about the good life. As you can imagine, the adults savoured the evenings after the busy days.

On the last day of our trip, we had a particularly notable experience. As we began to unpack, several other rafts floated up to the take-out point as well. The kids called to me that amazingly there was another raft on the river with a person who used a wheelchair. We soon noticed that actually there were three rafts who had people with disabilities. This was a "special" raft trip.

As we unpacked, a leader from the other group came over and said "Oh, you guys do trips for people with disabilities too." And I said "No, this is a family trip." We talked for a bit as I unpacked, and she asked me a number of questions. The first question was how long we had been on the river. I said "We have been on seven days." And she said they had clients with very severe needs and their clients couldn't tolerate such a long trip so they were only able to take a four-hour trip. She asked me how we fed our son on the river, because she said that

eating and preparing food was very hard for their clients and she didn't know how we would be able to accomplish this. I told her, "We used Wilson's gastrostomy tube and washed his syringes with all the other dishes using boiled river water with a little Clorox." She asked how we arranged for sleeping. They didn't spend the night on the river since some of their clients used wheelchairs and wouldn't be able to get in and out of tents easily. I told her "Two of us, whoever was available, lifted Wilson in and out of the tent in whatever fashion people could get him in and out." She asked who was on this trip to support our son since their clients required at least one adult per client to meet their intensive needs. I said "We all supported him. His dad and I did most of the feeding and gave him medicine, but the kids in his work crew did most of his other physical assistance supports during the day and helped him participate actively in whatever tasks their work crew was assigned." Then came the topic of heat stroke and heat exhaustion. She asked how we kept Wilson from wilting. "Well, we all wilted a lot," I said. With the squirt guns, swimming, water fights and tossing Wilson in the river when he told us when he was hot, heat stroke hadn't proved to be a problem. What about physical therapy while we were on the river? Clients with physical disabilities need therapy to keep their bodies working. I replied, "Well, we had no physical therapy for a whole week, but we had swimming, floating with a life jacket, stretching out on a hot tube of the raft, bumping through the rapids on a big cousin's lap and if you weren't too sunburned, you might get a lotion massage in the evening." The woman ended the conversation saying that she admired us and was glad that our son had the ability to participate with us on this trip.

The leaders of this special trip seemed like good people, trying to do good things for people with disabilities. But somehow this context was wrong. Interestingly, later in the evening as we were driving away toward civilisation waiting for a hot shower, my niece said to me that she thought it was very strange that this group of people had so many individuals who could walk, talk and do things that Wilson isn't able to do, but they looked so handicapped. And she said "I think it's because there were too many grown ups hovering around these people."

The points from this river trip story are simple. Wilson wasn't a client on our trip, he was another kid, a member of the family, one of the cousins on this trip. We didn't have any adult support staff assigned. Wilson didn't need it, though - I did! Wilson's needs took a little extra thought and a little extra work like everyday in our lives, just like home. But in the vast logistical process of living in the wilderness for seven days with all of these kids, assisting Wilson (whether by pureeing his food, offering a hand with physical assistance, or including him on a work crew) required only tiny extra steps. Besides we'd packed Wilson's umbrellas for adventures, had his food grinder to create guacamole and humus, and loaded his wheelchair to carry gear every day.

The big deal about our trip was the attitude and questions of some other people, often professionals. When some people learned about our planned trip, they got real quiet and asked us serious questions like, "Why would you take Wilson on this trip?" "Don't you guys need to get away?" "Wouldn't it be too dangerous?" "Won't it be hard?" "Would it really be good for him?" "What if he has a seizure?" Sometimes well-intentioned people who are part of the system perceive that people with disabilities can't do "seven days" because of the heat, food preparation, adult assistant needs and lifting into tents. Those issues are too great for them.

Now in case anybody is whispering - "they're an exceptional family" - I want you to know that we are not. We are just an average family. Our family happened to have the rafting skills to do this trip, but that wasn't the point. The river trip is parallel to many other situations in our lives and the river trip is a metaphor for Wilson being a part of whatever action is going on - whether it's being a counsellor-in-training at summer camp, adapting a bike so he can ride with his classmates, participating at the soup kitchen tomorrow assisting people who don't have a place to live or food to eat. Those are the action spots where Wilson wants to be. These places and activities need to become the programs in the system, not other places. We don't want programs or models or systems or special trips. Instead we would like to be offered support for things we need in our natural environments.

Navigating the river was much, much easier for us than navigating the school system that asks frequently why kids like our son should be in regular ed. all day. Don't we understand that he has intensive needs, that his needs are too great to be served in a school with no other kids with disabilities, that the specialists aren't there? Don't we understand that the school can't really do this or that? Don't we understand because he has a disability, he probably should be out in the community and not in the classroom?

Well, it's just like pureeing dinner on the river. Wilson needs to be where the action is, and we can offer the supports there. People with disabilities don't need spray bottles to keep them cool; they need squirt guns; they need action; they need fun and they need cousins and friends. Kids with disabilities need to sleep on a lumpy ground in a tent, even if their cousins dragging them through the door give them a bumpy ride. Wilson deserves to experience the challenge and stress of the river trip just like the rest of us. Surprisingly - or maybe not - on the trip everybody but Wilson became frustrated and blew their cool at least one time. But Wilson, in spite of the intense heat, having to be strapped into one position for long periods of time, being scraped and chafed from the life jacket, not being able to get those bugs away from his mouth, didn't lose his emotional composure. Wilson certainly deserves to ride through the rapids, feel the rush of the icy water in his face, and also celebrate the triumphs with his brother and sister and cousins.

So how does all of this relate to TASH? Well as TASH members, I am asking that we all work together to build a country where river trips can happen easily and people don't ask questions like WHY. I ask that we make the question HOW can we make it work? The system of support and services that we create must come to the individual and offer choices, resources, suggestions and opportunities so that everybody can have rich lives filled with as much adventure as they choose. No one should ever tell our family, or any other family, or any person with a disability that somebody can't do something because of their disability.

As a new Board member, I have been thinking a lot about what this important organisation can do for people. TASH is much more than this exciting yearly conference. It's much more than the *JASH Journal* that has articles that has helped us many times get the things we want. It's much more than the *Newsletter*, the committees, the executive board, the staff, the important resolutions, the governmental affairs presence here and the other things we do. TASH is also a values-driven bank of individuals who, I hope, actively live out the mission and make a difference day-to-day in people's lives.

This means that being a TASH member isn't necessarily easy or comfortable, just like being on a river trip isn't always easy or comfortable. It may well mean the opposite is true. Sticking up for what we believe is often hard work. It's risky because the system wants us to stay in the boundaries of current reality. However, realising the mission of TASH means pulling together and focusing on the important issues. It means breaking the trail, standing up for what's right, complimenting each other and walking beside each other as we work to make change. It probably means inconvenience, pressure, stress and political challenges at work, but being a TASH member, I hope, means acting congruently with our values. It means walking our talk and doing what's right.

There's a lot of work we have to do. The last month at PEAK Parent Centre, where I work, two families have called us. They have refused to put their children in school because the only option the schools would give them is a segregated classroom. So these families have refused services. The school districts are now charging the families with abuse and neglect for truancy for not sending their kids to school. There are criminal charges involved. Once that happens the families are having a hard time accessing their due process rights. Things like this are happening, and we as TASH members have to be the people who come forth, walk with families and work these things through. We can't just come to these meetings, go to sessions and not do what's right.

A final note, that I can't emphasise enough, is the urgency of these issues. I feel incredible dissonance when I learn about new things that could work very effectively for our son, but face resistance with the people in the trenches. When day after day I am asked to wait until the teacher becomes comfortable, or the therapist learns a new approach, or the administrator understands his or her responsibilities with inclusion, or the school board finds enough money to put an elevator into a building, I am incredibly impatient. Each day that happens, Wilson loses time and misses opportunities. Missed opportunities are a tragedy. All Mark and I can give our kids, all three of them, is a history of living a quality life filled with family, friends, learning, adventure and rich participation in everything around them. Every child and every adult deserves these same opportunities for a good life. A life where everyday counts.

And so, I ask for your hand and your help. Use the intensity and urgency that children, parents, and adults with disabilities present to all of us. Focus on good lives; follow what's right. Go around or go through or go over the political constraints that appear constantly. Don't look away, and please don't ask us to wait. TASH is committed to stretching the boundaries for what is possible. So I ask you to take risks, ride the river and build opportunities for children and families and adults with disabilities.