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Abstract

Louise Hackett, the parent of a son with autism, describes the National People First Conference she attended in Tennessee, America, and the issues which confronted her around independence versus protection for people who have disabilities. As a parent, she still struggles with these issues, and talks also about the support parents give their son or daughter and the support families themselves need. **Keyword: Families**

VIEWPOINT: A PARENT'S PERSPECTIVE ON SELF-ADVOCACY

By Louise Hackett

Over Labor Day weekend I was one of eight people who went to the National People First Conference at the Stouffer Hotel in Nashville, Tennessee. **Susan Langle** from the Division of Mental Health and Developmental Services and I accompanied six adults with disabilities on this wonderful journey. All of them are involved in self-advocacy groups in their region of the state. Three of us had never flown before, and many of us had never stayed in a fancy hotel. There were self-advocates from all over the country (including Alaska) and representatives from Canada.

The sessions were mostly run by self-advocates with assistance from advisors. There were many choices of sessions, with everyone determining their own selections. The atmosphere throughout the conference was one of festivity and celebration. The keynote speaker had everyone shouting "We have rights! We are free! We are powerful! We are People first!" Everyone, regardless of their disability, was accepted and made to feel just like everyone else.

There was music at all meals - someone playing a grand piano during the continental breakfast, a Dixieland jazz band at lunch, soul music at another lunch, and a bagpipe band at the last breakfast. During the conference there was also a country and western band, a rock band, and a Canadian folk singer, (the Vice-Pres. of People First in Canada), singing in French. Several times conference participants were invited to sing with one of the bands. One older

man played his harmonica with the country and western band - the first time in 30 years he had been allowed to play with a band.

In the sessions I attended there was a great deal of audience participation, and at times, patient redirecting. The personal stories of struggles for independence were amazing and thought-provoking. Their struggles with their families have left scars and in some cases, have left them estranged from their families. There was a powerful invocation by one of the participants, very simply and clearly asking for God's help in reaching goals. Another speaker talked about being free from group homes and other programs that see adults as little kids, free from silence and shame that keeps people from being all they can be.

This was an opportunity for people with disabilities to bind together and share common goals and common experiences. People with a wide range of disabilities all understand what it's like to be called names, stared at, treated like children. Even those with mental retardation shared in the common dream of community involvement and independence.

I experienced many emotions around these issues, not only at the conference, but also since I have come back. I cheered with those adults who have successfully fought for independence. I cried for those adults who have been rejected, either by society or by their families. But I also know the fear that comes

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with risk. For 23 years I have been the protective parent of my son with autism. **Tim** is unable to make many decisions on his own, but am I allowing him to make those decisions that he is able to?

Another issue that came up at the conference was the issue of dating and sexuality. Two young men were attracted to the one young woman with us whose mom is her legal guardian. I knew she had been entrusted to me because I was a mom, too. And yet, the general opinion there seemed to be that these people are adults and should be allowed to make their own decisions. And I'm left with questions like "But what about informed consent? Does the young woman understand the consequences of her actions? If the young woman gets pregnant, who is there for this older mom while she is making the right choice?" Luckily, the relationships did not progress that far, but the possibilities continue to haunt me.

So I continue to struggle with the issues of independence versus protection. There are no right or wrong answers to these dilemmas. We as parents of adults with disabilities face these issues all the time, and as we get older, risking is tougher. From what I experienced at this conference, I learned that it is important to listen to our adults, even if we do not like what they are saying. It is important to give them increasing responsibility and increasing independence even though we are frightened. And if our adults should strike out on their own, without our permission, we must never alienate them from their family. I heard too many stories of alienation at the conference. We must be there to support them if they falter.

We need to remember what we wanted out of life when we were young and give our adults a chance at some of those same things. In the past year I have given much thought about how limited Tim is in doing or having what he wants. He does not drive, has aggressive behaviour at times, and has little control in our home. His communication skills are limited, so we piece together what he says and decide whether he gets what he wants. If I let him have his own way, sometimes I am considered to be spoiling him. So again, it is a push-pull situation, taking much thought and patience. Sometimes I know I have made the right decision; many other times I'm not very sure. And at times I am caught between wanting things to stay the same and grabbing hold of the vision.

I believe that every family is different, every family can make changes only at their own pace, and every family needs support to make any changes. We probably go three steps forward and two steps back! The important thing is moving at all. We owe our adult sons and daughters that much. They all deserve new opportunities, and they deserve our support.

About a year ago I told my Area Agency that I needed Tim in his own living situation. At the time the main reason I even considered this move was that Tim is extremely tough to live with, and my family has been living with him for 23 years. He continues to be on a housing waiting list, and I continue to document the incidences that we handle in our home. Even before the conference, I was beginning to believe the professionals who said that Tim would gain more independence in his own place, that he had probably gained as much

independence as he could, living with his family. Since the People First Conference I know that Tim needs this chance. He needs a very individualised housing situation, but he deserves a chance at more independence. It does not mean that I back off and let the staff do whatever they please, but it does mean that I dare to risk.

I guess the main reason I decided to write this article was to reach out to the "older families", the ones with adult sons and daughters, the ones who have been through so many changes in the vision of professionals, the ones with ever-decreasing energy. To do the best we can for our adults while we are still alive, we must continue to find the courage to risk. We owe it to them and also to their unrealised potential. What do they really want in life and how can we help them get it?

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