

The Quiet Voice by Judith Snow

I am writing this message and sending it everywhere in order to reach as many people as possible who have been labeled disabled. There is an important day happening at the TASH conference in Anaheim on Saturday, November 17. The meeting that day is called Leading With a Quiet Voice. This will be a day for us to think and explore together what it means for us -- as people who are called disabled -- to be leaders in our own lives, in our communities and as advocates.

It is very important for as many people who are labeled disabled as possible to come on Saturday, November 17, from 10 AM - 4 PM. It is important because we have many things to share with each other and we have many questions to explore. Of course it is also important for people who have not been labeled disabled to come. But I am sure that lots of people who are labeled normal will come. Unfortunately, such people often go to important meetings without us. This time we must be there too because the purpose of the meeting is for us to find our own questions and answers.

My name is Judith Snow. I am a person who can barely use my body at all. Every day I live and work through the assistance of several personal attendants. I am 52 years old. All my life I have been around people who don't speak. I have often felt that I am a lot like people who don't speak, except that I do speak. My body is similar. I do things with the support of other people -- like most people who don't speak. I have been interested all my life in the way that people who don't speak live and communicate: I notice how so many other people treat people who don't speak as if they aren't really people.

Last year Rob Cutler asked me a question. Rob has autism and he mainly talks by using facilitated communication with Mark, his supporter. Rob is also the President of the Autism National Committee. He asked me: "How can we close BRI?" BRI is a hateful institution where people with autism are tortured.

Rob's question raised many difficult questions for me. I have not stopped thinking about Rob's question. **The real problem -- the really important question I think -- is: "How can people listen to us?"**

Advocates invent many strategies. Every strategy is meant to get someone more powerful to listen, agree and change how they act. People get together in groups. They raise money and hire people to make important points with politicians. They research facts and write papers. They block buses and roads. They create meetings and interrupt other meetings. They make phone calls and sometimes make enough phone calls to block the phone system. They hand out pamphlets explaining their ideas and experience. They make web sites and connect with other people's web sites. They light candles and hold hands. They sing and chant.

When people want people who are labeled disabled to be leaders they try to get us to do all these things. Rob was asking me how people with autism could do these things and succeed in closing hateful places where people are being tortured. Not one of these

strategies to make change was invented by someone who doesn't speak. All those strategies are difficult, and usually impossible, for a person who doesn't speak. They are also difficult, and usually impossible, for someone like myself who goes through life with the hands-on support of other people.

Why?

- It is difficult for us just to get together. You have to meet with people regularly and often enough to carry out sustained action. Often we don't have the transportation, attendants, energy, etc.
- We are usually dirt poor.
- We are often living in places where our activities are controlled.
- Writing and speaking often are not our best way of communicating.
- Nearly all of us have been physically and emotionally abused, even tortured. Many of us live lives where we are hurt every day.
- We are taught to not trust and not love ourselves.
- People who love us and support us want us to be safe and don't want us to challenge powerful people who can hurt us.
- People think that it is too bad we are the way we are. They don't listen to us because they think the "normal" ways of living are better.

Sometimes people who are called disabled break through and, like ADAPT or SABE, are successful at making change. But even these successes are limited when it comes to people who don't speak. Other advocates often don't include people who are not articulate.

For me there are other questions that are rarely asked and they are very, very important questions. I ask these questions because I think I am a leader and Rob Cutler is a leader, and many of us are and can be leaders. I think we need to find our OWN ways to lead so that we will be respected and successful. We need to find our OWN ways to get people to listen.

My questions are:

➤ Why are we called "dis-abled"?

We have different and unique characteristics. Often we are silent, or nearly so. Our bodies are unusually shaped. We are often fragile and frail.

We live in intimate connection with other people's bodies, minds and hearts. Our ways are not inferior to others' ways.

Living in this way challenges and extends our courage, our love, our empathy for others and our creativity. We see and hear what others miss entirely.

I am not suggesting that everyone should be like us. Our gifts are rare, and that is good. But, as difficult as our bodies and minds can be, their very uniqueness brings strength and

positive challenge both to we who live in these bodies and minds, and to society -- when we are appreciated, respected and celebrated.

We are unique and unusual people.

- **Why are we constantly being compared to the “normal”? What is important about us that is being denied? What are we and others turning away from?**
- **Where do our gifts find full expression? How do our gifts benefit others? How can this aspect of our lives be celebrated and shared everywhere?**
- **How do we naturally lead -- as our vulnerable selves and not as bad copies of other people?**
- **Who listens to us now? How can it be made possible that more people will listen?**

Leading With a Quiet Voice will be a day for us to explore these questions. We will explore my questions and your questions. We will share our lives.

We will not spend all day listening to people who talk. We will spend a lot of time in silence. We can move around. We can write comments or draw on the papered walls.

By the end of the day we will have made some personal decisions and some group decisions. We will take these ideas and decisions home. We will strengthen our leadership everywhere.