Testimony to the Senate Subcommittee on Disability Policy Hearing
Regarding Reauthorization of the
Developmental Disabilities Assistance and Bill of Rights Act
June 29, 1993

submitted by Sue Swenson

I live in Minneapolis, Minnesota with my husband Bill and our three sons: Will, who is 13; Charlie, who will be 11 in August; and Eric, who is 5. I was the third generation of my family to grow up in Red Wing, Minnesota, which is just down the road from Lake Wobegon. I went to college and graduate school at the University of Chicago. I thought my supportive family and good education made me ready to be a good parent. As it turned out, a program made possible by the Developmental Disabilities Act made more difference than anything else. I want to tell you my personal story of empowerment. Because of the DD Act there are many other people who have stories like mine to tell. I could try to give you numbers, but I couldn't dream of telling all the stories. I think the personal impacts of empowerment are greater than the numbers might show.

Ten years ago when Charlie was nine months old, his pediatrician first acknowledged that he had severe and multiple disabilities. I was pretty sure that the bottom had dropped out of my life. No one I knew had any ideas that could help me deal with the reality of raising a son who probably would not walk or talk, and who probably couldn't see very well, either. Like me, they had no meaningful or positive experience with people who have disabilities. My experiences were typical of the times: I knew very few people with disabilities and no people with severe disabilities. Carl, a boy who I now know had cerebral palsy, was in my kindergarten class. Our class had saltines from the cafeteria when it was Carl's turn to bring graham crackers because his family lived in poverty. At five, I thought his problems were caused by his family's poverty. The families who could afford graham crackers had no children with disabilities in the schools when I was a child. Carl and his brother drowned in the Mississippi River when they were seven and eight years old after Carl fell in and his brother jumped in to save him. My childish theory was that even mild disability ended in tragedy. My sister Barbara and I sang at the boys' funeral, and we also sang Christmas carols at the local State Hospital. I remember standing one Christmas at a locked door at the end of a long, green hall, seeing people's hands reaching out through bars in their doors as we sang. Later, in high school I knew Don a little bit. He was a big, strong friendly boy in my class. He scraped everybody's uneaten school lunch into the garbage every day, wearing a big rubber apron. I guess that was his job training, but it was a very tough job to do with any dignity. He never looked up while he was working. Over the years I collected the usual images from the movies like "The Miracle Worker," which taught me that good strong people can fix anything if only they never give up. If you add to that a few quick channel changes through the ridiculous telethons and a few passing glances at those ads offering a "loving environment for your handicapped loved one" in the back of magazines and some men panhandling from wheelchairs in downtown Chicago, you have about exhausted my whole experience with disability before my son was diagnosed.

I wish I could say we faced the challenge of our son's disability heroically, but we didn't. I spent whole weeks crying. We listened to all the pity and the platitudes, which only seemed to make things worse. We struggled. We couldn't find anybody willing to care for a baby with disabilities, so one of us had to be home all the time. As time went on and Charlie got bigger, we avoided taking our boys out, even to the park, because we couldn't cope with all the prayers, pity, stares, and outright hostility we encountered. We worked very hard on the therapies, silently hoping that Charlie would "get better" so we could go back to the real world. I went back to school to get an MBA, my second master's degree, so Bill and I could share the responsibilities of taking care of Charlie and making money in case Charlie didn't get better. We were pretty grim, even for Scandinavians. I remember that time as one long black-and-white Bergman movie.

Four years later, during the 1987-88 school year, Charlie was going to school in a segregated classroom for children with multiple disabilities inside a segregated school for children with disabilities, all the way across town from our house. This was the placement recommended to me as "the program we have for children like Charlie." I did whatever the "experts" told me to do, in the hopes that it would help, but I couldn't help asking questions. Halfway through the year, Charlie's new teacher, Cathy Carr, slipped me an application to a program called Partners in Policymaking which was offered by the Minnesota Governor's Planning Council on Developmental Disabilities. She told me it would be good to get some answers to my questions. I had to promise her I wouldn't tell where I got the application because there were several lawsuits about placements and a lot of tension in the school and she didn't want to be labeled a troublemaker. She knows how grateful we are that she took the chance. We laugh about it now. The application required a commitment from me, that I would attend all the sessions and do the homework. In return, I was promised a free, intensive program that would give me tools and access to ideas.

At Partners, my 30 classmates and I had a chance to get to know national leaders like Ed Roberts, Ian Pumpian, and Lou Brown and real moms like Fran Smith and Betty Pendler who told us what was working out there. They told us how they felt and what they thought about disability. They taught us to use people first language. We learned the history of the disability movement, from the parents' movement right up to People First. They told us what they were working on. We learned about independent living, supported employment, and family support. We learned how to use assistive technology and how to access the human service system. We learned about personal futures planning and whole life planning.

We also learned what Congress was working on. They told us about the ADA. They helped us sharpen our vision of living in a world with no restrictive environments. They challenged us to find our own path, our own beliefs, our own commitments.

We learned how to participate in the policymaking process and how to work effectively with professionals and public servants. We learned that we were the most reliable experts about what our kids needed, and about we what we needed if we had disabilities ourselves. We learned how to run a meeting, how to testify, and that we should testify. After a tough college and two master's degrees, it was the toughest learning I ever did, because it was so real and so important to me and to my kids.

In those nine months, we came together for two days each month and worked on homework in between. I remember realizing at the first session that there were responsibilities that went along with all this learning. It was a new idea to me that there was or ever had been a civil rights movement among people with disabilities. I don't remember how it happened, but slowly I became aware that I was no longer working on fixing Charlie so my family could "go back" into the real world: now I was working on changing the attitudes of all those ordinary people, so they would see the value of communities which include people with disabilities and all people. I was working to help my friends and neighbors see that we all live in one world. It is important to me to see to it that other children wouldn't grow up as I did: removed from any possibility of understanding the variety and richness of the human community, left without the ideas I needed to deal with disability in my own family.

In Partners, I learned that I could stop trying to make Charlie into somebody he wasn't. I went home from one session feeling as confident as I've ever felt, and told my husband, "Don't worry, it's okay, we don't have to change Charlie. We just have to change the world." Now, I know I can't change the world alone, and Partners doesn't teach people to think you can do it alone. Instead, Partners empowers people to do their part to change the world and make it more inclusive.

In Partners, I learned that the way to change the world is to focus on what you need to live your life, to speak up, and to participate. We learned to be to secure in the belief that we were the best experts on our own needs. We learned that people need to be in charge of their own lives, even if they happen to have a disability or a child with a disability.

Because I say that everyone should be included and that self-determination is possible for people with severe disabilities, some people have called me a radical. If it is radical to believe in the principle of self determination, then I am a radical. If it is radical to be suspicious of the opinions of experts who want to tell me what is best for my family, then I am radical. If it is radical to think my son should be in charge of his own life, then I am a radical. Viewing experts with suspicion is an American tradition. Devotion to self determination is an American tradition. Belief in the dignity and value of the individual is an American tradition. So perhaps I am a traditional American radical just moving on to 'the last great inclusion of American life.'

I sometimes think that Thomas Jefferson would be happy to know that the principle of self determination is still considered radical by some Americans after 200 years. Jefferson's fruit of revolution continues to ripen on the tree. Perhaps revolutions in families and schools and communities are quieter revolutions than Jefferson knew, but they are no less real. Since reading Joe Shapiro's <u>No Pity</u>, I have begun to quote T.J. Monroe on the subject. He said: "This is a free country. You can talk for yourself. You might need some help, but you can talk for yourself." That seems like a fine traditional American radical sentiment to me.

In Partners, I learned to speak for myself and for my family. I learned to listen to Charlie better. First, I learned to ask for what we needed to keep Charlie living with us. A month before I graduated from Partners, Charlie got enough personal care attendant services to allow him to have some independence from me and to allow me to work full-time. A few months after I got the job, my company's health insurance bought Charlie's power chair. Our family isn't falling off the edge anymore and we hope to be able to send our sons to college. (I have always said that a fraternity house will be Charlie's only experience with a group home.) We're still a little groggy some days after Charlie has been awake for several hours in the night, as he is about half the time, and now we need an elevator in the house. Charlie still lives with us and generally we are all doing very well, even though the problems go on and change. (I would like to ask to be invited back when you address the delivery of services and supports.)

In Partners, I also learned what went into a good educational program. In the last four years, Charlie has gone from a segregated school to a segregated room at his brother's school, to part-time inclusion, to full inclusion. In 1989-90 I negotiated for ten minutes of inclusion during story time after lunch in a second grade down the hall from the "special" room. After a week, the kids insisted that he didn't want to go back to the "special" room, so he stayed all afternoon from then on. The next year, he was included full time in that second grade, and the year after that we completed an elevator which allowed him to move to a fourth grade with his age-mates. Last year, his collaborative team (including teacher Susan Bell, paraprofessional Mike Alexander, special resource Carol Kramer and speech teacher Ann Davis) and his classmates introduced Charlie to facilitated communication, which allows Charlie to communicate by spelling with facilitation from another person. This year, he is included in a fifth grade where he is doing math at a fourth grade level. He reads pretty well if the book is held upright in front of him, and answers questions about what he reads. When I asked him what communication meant to him, he spelled "power." When I asked him what kind of power, he spelled "touch" and "kognutiv." Later, I realized he meant "cognitive," a word he has heard for years. His spelling has been phonetic, but he is learning to spell better. He reads music well enough to recognize simple scores when he hears the music played. He recognizes composers. He doesn't cry and yell all day as he did in the segregated room. If you ask him how he learned so much, he tells you "by listening." He also will tell you "I am a very smart boy." He is proud of himself. He won the wheelchair race during field day last month, and one of his classmates complained that it wasn't fair because he got to practice all the time. She didn't even mention his electric motor. His classmates voted him "most popular" at the end of the year, and he is developing friendships with other kids both inside and outside of school. The friendships are the key, what it is all about for us. **Sustaining the positive force of friendship in Charlie's life is our real goal.** I want to share with you two notes that were in Charlie's backpack on the last day of school. One from his teacher, Mary Lou Hoff:

> "Dear Bill and Sue, Just want you to know how much I've enjoyed getting to know Charlie this year. Despite some initial doubt and skepticism, I can't begin to tell you what a powerful experience it has been for me both personally and professionally. Charlie's presence has had such a positive impact on all of us. As he and his classmates have interacted throughout the year, I have seen relationships develop and grow on a level I wouldn't have thought possible in September. I'm sure I speak for all of us in 204 when I say Charlie has touched us deeply and we are the richer for it. Thanks for the commitment and support."

And one from Charlie's new friend, David Ribble:

> "Charlie is the coolest kid. I have lernd alot from him. We plade at reeces, we talked. I really like Charlie. p.s. I wood realy like to come over. I nowe you say just call but my Mom ses I can't call you have to invite me."

The spelling is my favorite part. It shows there was no grownup coaching him.

There are lots of good people out there – policymakers, bureaucrats, academics, other parents, kids, neighbors – who want to do the right thing. They may need to hear what the right thing is a few times, and why it is right, but after they get it they dive right in. I was taught to challenge people, to help them understand, to show them a new way of thinking about people with disabilities. For people with disabilities, change really happens in their schools, neighborhoods, and families and in the hearts of all these fine and ordinary people. As Joe Shapiro points out, Congress can sponsor this change by giving us the ADA, the DD Act, and IDEA, but we must take it to the people, one by one, before the real changes happen.

When the change to inclusive thinking starts, it is amazing to see. Now sometimes I just stand back and watch. I worked for two years to get an elevator in the school, but the next year the principal decided to close the segregated classroom without more than a hint from me. All the kids are included now, and new applications arrive constantly. Parents of typical kids are requesting inclusive classrooms because the atmosphere is one of collaboration and belonging. In Minneapolis, parents choose their child's school, and Charlie's school, Fulton School, is now one of the most popular elementary schools in the city. Our new principal Frank Hinkle was also new to inclusion last Fall, but now he is spearheading a city-wide inclusion Task Force – 120 people came to the first meeting, representing 30 schools. Our next meeting is June 30 and we expect even more people. There are 43,000 children in the Minneapolis Public Schools, 5,000 of them with IEPs and we're working on full inclusion district-wide. We are guided, as we ought to be, by the principle of 'no restrictive environments' set out in the ADA.

I haven't sued anybody, and I haven't used a professional advocate. Maybe I was lucky, or maybe the system responds better to people talking for themselves, and focusing on creating partnerships. For my family, achieving inclusion has not been an adversarial process. Now, I know there is just no way I'm changing that school district to be inclusive by myself. But I am a full partner in the process, and only because of Partners.

Since graduating I have served on several boards and committees, including my local ARC, the state and local Special Ed Advisory Committee, and Fulton School's site-based leadership team. I have also participated in training sessions for other states preparing to offer Partners programs. I have also been trained by the Administration on Developmental Disabilities to be a consumer reviewer of university affiliated programs. I helped review the Minnesota UAP last September. They said then that they welcomed my challenge to be responsive to the needs of their chain of clients, and to the end user. They want to be more accountable for outcomes, instead of for compliance with pre-set standards. They want to try new ideas, but they also want to have a way of knowing whether their ideas are doing any good. By the way, I attend my first advisory committee meeting at the UAP's request on June 28th, so whether they liked what I had to say in the review or not, they're in for a lot more of the same.

Of course, some of the academics in Minnesota and around this country know the truth already and they don't need any consumer's opinion of the usefulness of their theories. Certainty comes with the territory. (My husband is an academic. Some of my best friends are academics.) I believe that the DD Act should encourage academics at UAPs to demonstrate that they understand their mission is to train people to teach and work with people in the next few decades, not in the previous few decades. Which to me implies that they need to be developing new ideas, not promulgating old ideas, or safe ideas, or esoteric ideas. They should not have to worry so much about appearing foolish if they try something that can't be proven valid beforehand. Felix Cohen said in his essay "Indian Self Government":

> "Of course, we must all start with the assumption that we are right or as near right as we can be. But can we not also recognize, along with Justice Holmes, that time has upset many fighting faiths, and that even if we are possessed of absolute truth it is worthwhile to have somebody somewhere trying out a different idea."

Everywhere I look – in business, environmental programs, health care, and education, I see organizations using continuous quality improvement principles and customer satisfaction measurements to improve what they do, to guide the development of new ideas, to keep them on track. But I don't see accountability to clients, customers, and users in the programs supported by the DD Act. People with disabilities and their families should not be denied the opportunity to judge the effectiveness of programs intended to help them. As these findings make abundantly clear, disability –

even severe disability – does not mean people don't know what works for them, or what they want.

As Aristotle said in his Politics, the person who lives in the house is the best judge of whether the house is good – not the architect. Or from Felix Cohen again, "America, despite all the lingo of the administrative experts, has insisted upon self-government rather than 'good government,' and has insisted that experts be servants, not masters." As these findings state, our systems of support delivery are not yet responsive to the highly individual needs of people with disabilities and their families.

Therefore, I believe the draft before you would be strengthened if the systems which are responsible for innovation, systemic change, training, and information dissemination were made more accountable to clients, customers, and users. I do not see how they can help create more responsive systems if they do not measure and improve their own responsiveness along the way.

Partners in Policymaking, as conceived in the original Minnesota model, is responsive because it tracks outcomes over time by asking the participants what they think, what is useful, what could be strengthened, how the program could be improved. Empowerment and leadership programs are responsible to the people who have to go out in the world and use what they know. If Charlie and I had tried to do what we've done with less complete training, I think we would have failed. And we didn't need another failure. Paper wings wouldn't have carried us. We didn't need a support group or an information clearinghouse - we needed a thorough education.

Organizations other than the Minnesota Planning Council on Developmental Disabilities are offering Partners. Many are excellent and effective empowerment and leadership programs for people with disabilities and parents of people with disabilities. I believe the draft in front of you could be strengthened by adding language which makes the responsibility to clients, customers and users clear to Councils and to any other organizations who offer empowerment and leadership training to parents and people with disabilities.

I work with professionals. I have worked for lawyers and doctors, and now I work for a large firm of consulting engineers. They are all using quality principles to guide their service improvements and their responses to their clients' needs, and to help them design their future services. Every organization with which I have ever discussed quality improvement begins by saying that it is a great idea, but would never work with "our" clients. Others say that quality is only for competitive environments, but I believe organizations in non-competitive environments need to go to extra lengths to make sure they are responding to people's needs.

I know there are hundreds and I believe there will be thousands of stories like Charlie's if the DD Act continues to encourage experimental, outcome-driven, change-making programs like Partners in Policymaking. Twenty states have completed training sessions modelled after Partners, and 35 states have been trained to use the model that was developed and tested in Minnesota. There are now 1200 graduates. I don't speak for them – they can surely speak better for themselves – but I have had an opportunity to meet some of the graduates at a Texas training academy for states interested in creating Partners programs. Partners can't help but make a difference, in each of their neighborhoods, cities, counties and states. It might take time. Empowerment begins in your own home, with your own family. People often need to do significant work to get their own support systems in place before they can have enough control to be as involved as they want to be in policymaking issues. For my family, it took three years to get things lined up for Charlie, but last year I gave about 300 volunteer hours working on systemic issues. Some Partners still must struggle with finding transportation to the meetings they want to attend. When they get that solved – and they will – the pattern of empowerment, commitment, and determination will emerge.

I am now beginning to target "generic" organizations rather than special disability organizations, such as environmental groups, generic school advisory committees, and business organizations. Many Partners are well beyond that: some have run for office, several are planning to run for school boards, and some have spoken at international conferences. It might take ten years, but the impact of Partners will be felt.

The DD Act made these outcomes possible. As you continue and strengthen the purposes of the Act, please know that the Developmental Disabilities Assistance and Bill of Rights Act makes real and meaningful differences for people with disabilities and their families.