

## Planning Statements

### The Status of Disability Studies in SDS and its Impact on Disability Policy

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Without doubt, I can present myself to you as the oldest living past-president of SDS. I could even do that when Irv Zola was alive, since I was a year or so older than he. I don't know what that can buy me, but I'm hoping at least I can have your focused attention, because, from my vantage point, I feel that I have some things you as members of this organization should consider carefully, thoughtfully and immediately.

I could go into a history of the organization and my interpretation of how things came together and have evolved over the 15 years this organization has been in existence. Everyone will have a somewhat different view of that. While that would be an interesting bit of nostalgia, it would not accomplish what I have in mind. For those of you who are interested in some of those details, I'm happy to answer questions later, but for now I would like to focus on today, the present and the future of SDS and Disability studies.

First however, I would like to take a page out of Irv's book and tell you a story.

A little over a month ago, on a beautiful Sunday afternoon, I was on my way to the office to work on a paper that needed to be finished. You know how it is during the work week, interruptions, phone calls, e-mail, meetings, all contribute to preventing you from having large blocks of time when you can 'think' and write. Well, I turned right on Barkwood street as usual and drove down to the stop sign directly across from Lucy Barnsley Elementary school, stopped and looked right and left before making a left hand turn onto Nadine. It is something I do every day of the week. I noticed how much quieter the street was than on workday mornings when children, parents and teachers are usually making their way to the school.

After I completed the turn, I heard a sharp whistle and some choice curse words. As I looked about me trying to find the source of the noise and to see if it had anything to do with me, I saw the top of a helmeted head pass me on the right side of the car. As it pulled in front I saw a wheelchair athlete in a low slung v-shaped vehicle going at least 35 to 40 miles per hour. Obviously I had cut him off - but I never, never saw him coming. As he sped to the next corner and I hung back giving him a lot of space, I felt terrible. I only wanted to say, "I'm so sorry, I know about disability problems, I'm not like other insensitive people."

As I approached the corner where he had turned right, I realized how silly those thoughts were - being disability-conscious had nothing to do with what had happened. It wouldn't have made a bit of difference if I had been in any other motor vehicle, with or without a handicapped license plate, the damage done if he had been hit, would have been the same.

When I turned right at the corner, I saw him stopped behind a parked truck waiting for traffic to pass so that he could go around. I slowed and stopped as I approached him, put down my window and leaned over to apologize. I told him in all sincerity, I had never seen him. He replied, "that's ok, I look out for myself." I went to work, but it took me days to get over that experience. When I drove to work each morning and stopped at that corner, I went over in my mind again how I could have missed him.

My only conclusion was that since he was very low to the ground and my Miata is also low to the ground, if cars or vans had been parked at just the right place on my right, I might not have seen him coming. I'll never know, because I don't remember what if anything was parked there that day. But I have come away with two lessons from that experience. Two things I want you to keep in mind during the rest of my presentation.

1. It doesn't make any difference who is behind the wheel, the damage done is all that counts.
2. We all have to take responsibility for ourselves at whatever level we can.

I'll come back to these later, now I want to talk about SDS.

Let me tell you about some of the changes I've observed in this organization during my tenure. I want to talk about membership, meetings, purpose, and impact or effectiveness.

### 1. Membership

Membership in my book has been both positive and negative. Membership grew substantially in the 1986-90 period when we moved from meeting with WSSA<sup>7</sup> to our own separate meetings. However, our membership number has been at best stable, more likely somewhat lower over the past several years with a good deal of turnover, that is people who join, but do not renew the following year or two. I don't have exact numbers, but that is my impression from reviewing the membership list. We have increased our numbers of members who have visible disabilities, but it is my impression that we have lost membership among persons without disabilities. We are not attracting a broad range of persons who do disability research, particularly some of those who are relatively prominent in the field. We are certainly not the primary organization for many prominent researchers in the field.

### 2. Meetings

We are managing to field a meeting every year and those meetings have taken place in a variety of geographic areas. For the most part accessibility to meetings has improved each year as we have learned from previous problems. However, while I don't have access to meeting attendance information over the past few years, I think that the number of submissions of actual papers (not panels) is down and that the quality is lower generally. I also am under the impression that meeting costs are not being covered by meeting income which can become a drain on the organization treasury over the years.

I have personally invited colleagues who are either doing very interesting work or who are new to the field to attend these meetings. Not one person has come back and several have indicated to me their dissatisfaction with their experience, particularly noting the lack of scientific excellence and the subjective criticism they experienced. Which brings me to my third point:

### 3. Purpose

We have a very nice statement of purpose on our membership form that was changed somewhere along the line, after my tenure as membership chair. I'm not sure that designation of purpose is what is actually happening. I don't see that attempts to increase membership is continuing to bring diversity of disciplines or members into our ranks. I also do not see our scientific purpose strongly reflected in the review of paper submissions or the organization of sessions with discussants to critique presentations. I don't see the professional development types of activities necessary in a professional organization, that includes workshops on new and interesting methods, presentations about data that can support disability studies research (other than the NCHS data and the ICIDH) and providing of funding source information and grant proposal writing information. I know a program for mentoring our young researcher has been started, and that we do have ongoing presentations on teaching about disability which have been quite useful.

### 4. Impact

Where do we see our impact? What kind of impact do we want to have. We have to establish ourselves as expert scientists in this field in order to gain recognition or our work will never be respected and provide the type of contribution to disability policy we want to make. We have played with the idea of a journal for years and the indication was that membership levels are not high enough. This should finally be getting intolerable because we sit here without a voice with which to address the policy arena.

I think it is time to start pursuing success and stop circling the wagons staying on the same spot we've occupied now for 10 years.

A. We need a real examination of our purpose and our audience. What kind of impact do we want to have on the research and policy community. In other words, like the wheelchair athlete, we must be prepared to take responsibility for ourselves. Its time for this organization to decide on its goals. Is it a social club for those Goffman called "the wise" or is it an intellectual enterprise that seeks growth, influence and respect. This organization was never conceptualized initially as a consciousness raising or advocacy group but that is the impression it gives to strangers.

B. After we decide the purpose, we need to examine what makeup of membership we need to accomplish that purpose. It is here that I would consider the impact of a product rather than the person who creates it. As in my story of the wheelchair athlete - it makes no difference who is behind the wheel or the computer which produces the research. The product is either damaging or useful. It is to our advantage to have the opportunity to point out to an author, the errors in conceptualization or method before the damage takes place. All should be welcomed and judgement should be made on the quality of the work, not the disability credentials. If we focus on the work and recognize quality while educating on the pitfalls of the medical model, we will contribute to the creation of a respectable body of work and to our reputation. We also need to provide a safe forum for differing opinions, and constructive criticism. Growth comes from both. To be unwilling to allow for disagreement or unable to provide intellectual criticism means we will continue to stagnate.

I challenge you as members and your Board as leaders to delineate and face this issues now, so that SDS has a future. It may already be too late to undo the reputation we have acquired for advocacy orientation and scientific immaturity.

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