Summary Comments on the International Disability and Diversity Studies Institute, Center on Disability Studies

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At the beginning of March 2002, preceding the Pacific Rim Conference, the Center on Disability Studies at the University of Hawaii, Manoa, sponsored a preconference symposium called the "International Disability and Diversity Studies Institute." Scholars throughout the US and Australia were present to discuss their work. The audience was made up of faculty, graduate students, members of the community, and rehabilitation professionals. Presenters were grouped in pairs. After each pair delivered their remarks, the large group broke into two groups for comments. The smaller groups were joined by the two previous speakers, a facilitator with a video/sound crew, and myself - to give the group an overview from a disability studies perspective. Although the notes taken for this process were initially for my own short term use they may provide some insight into the remarks of the presenters. What follows is a list of presenters in chronological order, accompanied by some of my observations.

DAVID PFEIFFER

One of the key individuals planning this symposium, David led the presentations with a scholarly dissection of historical perceptions of disability. He spent much time laying the groundwork by describing who has traditionally had the power over people with disabilities, politicians, psychologists, physicians, and other such "helping" professions.

David spent some time discussing the Society for Disability Studies (SDS) and some current debates among its members. This was followed by a question for participants regarding what we would like to see at an SDS meeting offering examples such as health and quality of life issues.

RICHARD SCOTCH
Richard took a narrower look at disability studies: how it is looking at research possibilities in the present. His focus was more on how disability studies is becoming more "consumer controlled" in present day, how instructors look at disability and the perceptions of others as well as our perceptions of ourselves. This included how we have moved along a journey from viewing our disabilities from shame to pride.

MY VIEWPOINT

My viewpoint found the combination of these presentations exciting and a strong jumping off point for the symposium. The issues raised touch upon a cornerstone of the Independent Living Movement - the idea that we may well be the experts on our own lives and if we were not, then we needed to learn from our peers. We are well served to take a look at our history. It helps us to understand the history of our "place" in society in terms of attitude, education, and work, for a start. It helps us to understand our lack of self esteem. It was a starting point to the journey to a place of pride. It is only in recent years that we have been paying attention to documenting the journey to a better self image and how we have begun to see ourselves with pride in some parts of the world.

GOPAL PATI

Gopal provided a good overview of the history of employment of the disabled, particularly for those who are deaf and/or blind. He also spoke of increased employment for people of short stature during World War II with their ability to fit into tight places, especially small engines for repair work. He set the mental playing field in his presentation of the more traditional approach to building a rapport with employers that would open the door for employment opportunities for the disabled. From his viewpoint these are approaches that are still appropriate today. Governmental departments polled feel these approaches are working well and that by and large the American with Disabilities Act is well supported. He also spoke to other statistics showing that employers are winning 91% of the ADA employment suits filed, there are some 179,000 disability related cases still on the dockets, and that we still have 70% unemployment among disabled in this country.

DAVID MANK

David presented a different perspective, focusing on the present and (hopefully) the future. Today's approaches still include education of the potential employers (although this is not a widespread practice) and includes things like supported employment for people with developmental and psychiatric disabilities. Issues regarding expected behaviors in the workplace are often best addressed by peer pressure and role modeling. New possibilities for living and making choices are being included in teaching disabled people that they can be who and what they want in most cases. The widely applauded group home concept of 20 years ago is seen more and more as settings that do not really promote independence. David also addressed the need
for training for teachers in seeing their students as whole people with many possibilities, added to that is the need to utilize technology to widen the horizons for all.

MY VIEWPOINT

Admittedly, I first thought of Gopal Pati as being a bit "old school" for my taste. Taking what felt to me as the slow road to change. But then I was taken back by what I saw going on in the 1970-80s in the movement when there were heated arguments as to whether we should create change by educating people first, and changing laws later, or if we should plan on a demonstration and media coverage as a path to change. It was the blend of approaches that worked then and continues to have success now. One of the purposes of the movement was to learn we have uncountable choices in the world. This includes a variety of choices in our approach in solving problems. This led me to having great respect for the work Mr. Pati does.

David Mank really gave a great example of the benefits of consumer control where we are seen as some of the experts of our needs. We have successes and failures and learn from both. We need to become good teachers of the "helping professionals" so they can acquire the skills needed to work with us.

STEVE BROWN

Steve gave a presentation on Disability Culture looking at it from many facets. He was able to touch upon some of the historical aspects as presented by David Pfeifer and Richard Scotch as well as address some of the issues of the journey from shame to pride. He accomplished these things through the reading of poetry, lecture, music, and video and gave everyone a vibrant and powerful expression of the disability experience. Since I am the co-founder of the Institute on Disability Culture it is hard for me to write from the perspective of a symposium participant. That coupled with the multi-faceted approach to his presentation I believe that it makes it difficult for a person to really "get it."

MEGAN JONES

Megan provided some different perspectives of Disability Culture as experienced from a blind and deaf perspective. It was a fascinating view of a journey: her identity as a deaf adult, her identity as part of a deaf culture both brought about a conflicted feeling of whether there is a disability culture. At the same time she gave many examples of how deaf culture came about and how she sees similarities in a disability culture. This left her with a feeling of "struggling to hold on to my normalcy." She sees the social "stigma of disability as being a bonding factor for gathering crips together," and that stigma as being part of the road from shame to pride. She is still somewhat conflicted with the difference of those trying to be accepted as they are and those trying to fit into what they think of as "normal." What is the difference between Disability Culture and a disabled community? There is much food for thought.
As I mentioned earlier, I feel that the concept of a Culture fits in with some of the basic tenets of the movement - not only in the US but abroad. The idea of a Disability Culture is an inherent part of the shame/pride journey mentioned earlier. There are stages of growth. The following include some rather generalized statements, but bear with me please. A child is either born with or acquires a disability early in childhood. He/she is early identified as the "problem" or "difference" in the family, not normal. Many identify this as a time when they began to feel bad about themselves and began to strive for "normalcy," a kind of normalcy society rarely awards us. So, which identity do we go for? What journey do we embark on to begin to address the issues such as the ones that Megan put forth so openly and clearly. She brought forth much food for thought that I would like to see studied more completely: not only with deaf and blind identities, but with people with other disabilities that have not been included since the inception of what is referred to as the IL movement.

PAT MORRISSEY

Pat's presentation gave a concise overview of how disability policy has changed over the years from a governmental viewpoint. This includes how US policy has changed with the influence of other nations with whom we are allied. For example it was the British and French who took a look at quality of life for people with cognitive disabilities - the solution: institutionalization.

In 1984 she was sent to a conference sponsored by the Panamanian government to address quality of life issues in developing countries for people. Pat presented the American approach "without thought" to cultural differences. She quickly learned from her assumptions and altered her approach to people of different cultural backgrounds.

In the mid 80s to late 90s there were significant changes to Section 508 of the Rehab Act: any electronic equipment purchased and accessible to government usage is mandated to be usable by disabled people.

The incentive to work program is changing focus from national government to state to state guidelines. From there it is hoped each state will create its individual programs to employ the disabled.

KAY SCHRINER

Kay provided an overview of the voting rights history (for disabled) in Hawaii and in the US. Until the 1950s it was prohibited to allow someone considered "non compus mentis" to vote. There was (and is) the need for the disabled to become a political voice to direct change. There are still many laws across the country prohibiting people with various disabilities to vote. Most are unaware of these laws and therefore nothing is done to have them expunged from the books.

The issue of giving states control over implementation of Disability Rights laws has not gone well, but no one is fighting it on the larger scale.
MY VIEWPOINT

From a Disability Culture perspective I start with a question: has anything changed substantially? This does not mean, have these women done anything to create change? It goes without saying that they have, that there are too few trying to hold back the old ways and create change at the same time. The whole governmental approach to employment and independence still comes from the caretaking/charity model. Starting in the late 1970s and into the 80s it became more and more clear that the disabled community in the US had a growing sense of what a strong political power we really are. We have stopped paying attention and have become apathetic just as our numbers and energy are needed most. The passage of the ADA in 1990 was presented as a milestone for disabled people in the US and the world. It took awhile before it really became apparent how many loopholes were built in to this act - giving the government a multitude of ways to undermine our rights - in spite of the long hard work many people put into closing the loopholes. Already we can see the failure of work incentive programs in Japan and Germany. They both have a 4% employment mandate. Businesses that do not comply must pay a penalty. This money goes into a fund to make public places accessible. In both countries these "funds" are overflowing with "penalty fees".

Lillian Gonzales Brown, is the co-founder, along with Steve Brown, of the Institute on Disability Culture in Las Cruces, New Mexico. She is a recognized leader in the disability community specializing in independent living training. She is nationally known as a consultant to organizations of people with disabilities and an outstanding advocate.