

A Reikjavik Journal

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Over 700 people attended the International Conference in Reikjavik (June 1994), of whom about 350 were from Iceland. There seemed to be representatives from every corner of the earth. Many groups and associations of handicapped persons were present to make presentations and to participate in the conference. The conference theme vacillated between the one identified in the conference title, *Beyond Normalization: Towards One Society for All*, and the presentation and discussion of the United Nations *Standard Rules* on the Equalization of Opportunities for Persons with Disabilities.

In a sense, the conference was something of a great experiment in the creation of a "society for all." The conference was very, as I've heard say, "inclusionist" in that there was a great attempt to insure at the outset the highest level of physical integration, accommodating persons with various types of disabilities and from various nations. Moreover members of most groups were given the valued roles of presenter, moderator or discussant. The *Standard Rules* of the United Nations were the backdrop or even the inspiration for this great happening. Thus, we were invited to create a great social utopia. But at the end of the three-day conference, it was clear that the moment was lost and the spirit that people had wanted to foster never happened.

And yet the experiment had been well designed to succeed. The conference was held in Iceland, a very prosperous, hospitable and engaging country. Icelanders bent over backwards to provide us with hospitality, kindness and helpfulness. The conference organizers clearly wanted it to be the event of the year, providing a rich and glittering environment for such an experiment.

The speech by *Mrs. Vigdis Finnbogadottir*, the President of Iceland, was probably one of the better political speeches on integration that I've ever heard. She is clearly an estimable person, full of good will and seemingly very brilliant. She told the story of *Leif Erikson* -Leif the Lucky- who was known as "lucky" because he had saved the lives of a number of marooned mariners. Thus, in Nordic culture, luck was associated with helping and especially saving lives. Throughout the conference there were intermissions of classical music which gave us an all too brief taste of Icelandic culture, a very high culture indeed, and Icelandic mores. It would have been very hard for anybody not to fall in love with Iceland during this visit. Reikjavik, though, is a relatively small city (100,000 people), and the conference taxed the city's capacity to welcome such a large and disparate group. There were a number of mix-ups and confusions at registration and for the presentations. Many of the physical settings were clearly not accessible to persons with physical limitations. Conference organizers found imaginative though not always enhancing solutions to some of the problems of accessibility. For instance, the main stage of the beautiful conference hall was very high and the conference organizers set up an unsightly forklift for persons with wheelchairs who had to be led up to the stage. We all closed our eyes with embarrassment at this and hoped that this would not be the prelude of things to come. But there were only a few such unfortunate incidents.

The conference participants -the subjects of the experiment- were also very well selected to make the project succeed. The 700 people who attended the conference were the engaged and committed who wanted good things to happen for persons with disabilities. There were representatives from most disability groups, though I did get the impression that mentally retarded persons were underrepresented. More than half of the presenters were women, though the representatives from the Third World were in a minority.

And yet the whole experiment broke down.

The conference rapidly segmented itself along very predictable lines.

Consensus did not grow during this conference. Rather, the lines of differentiation became much more clearly visible than ever before. This became especially clear when physically disabled persons became very angry and demonstrated at this and that workshop, where they expressed outrage at the idea that non-disabled persons could speak with any kind of authority or knowledge about disability. Some American parents of handicapped persons, who had made presentations about school inclusion, challenged others when they were not themselves parents of such children: "how dare we speak about the problems of handicapped persons." And there were those normalization/SRV types who tried to say that devaluation is a hard and complex problem and that it would not be easy to reverse it. But this last group was the meekest of the lot, though they inherited nothing during the conference.

Maybe the conference wasn't long enough and maybe the experiment did not run its course for enough days, weeks, months or whatever, but clearly the whole notion of one set of rules for one society did not make much of an impact on the spirit of the engaged and committed. The notion that we could rule, legislate, or even think our way into a better society was shown to be an empty idea for the very goings on at the conference.

Some Interesting Workshops and Interesting People

Over 100 persons made presentations at the conference. Many were outstanding. Some of course were very poor. I selected certain workshops that were interesting to me, and I therefore can't claim to give you a real flavor for all that was going on. But it was a very busy and ambitious conference.

Prior to the conference, *Doug Biklen* of Syracuse University and some of his colleagues were present to give extended workshops on Facilitated Communication (FC). Clearly at the conference there was a great deal of interest in FC and *Doug Biklen* and colleagues were, in some ways, the stars of the conference.

Marius Berentsen of Oslo in Norway critiqued the notion of appropriate housing. He suggested that current standards of housing for physically handicapped persons were as bizarre and offsetting as to be tantamount to segregation. His presentation was very forceful.

Paul Ramcharan in his presentation: *Extending Models of Empowerment to Everyday Life*, made some very powerful comments about SRV and normalization. But he made a particularly interesting point vis-à-vis satisfaction, expectations and service quality, namely, his finding that very often a high level of satisfaction is associated with low expectations, and conversely that low satisfaction is a product of high expectations. Thus he suggested the possibility that service quality has little bearing on client satisfaction.

Dr. Philip Ferguson of the University of Oregon in the USA in his presentation, *Families and Professionals: a History of Resistance and Accommodation*, gave a brilliant presentation based on stories gleaned from family correspondence and family journals, in the 18th and 19th centuries, about how families had to deal with the presence of handicapped children. *Dr. Ferguson* has recently written a book on the same subject that shows that the tension that exists between the formal (service) system and informal (family) system is longstanding. These powerful and poignant stories of the past are very relevant to the current struggles of parents with the professional service system.

Ingibjorg Audunsdottir, a mother from Akurere in Iceland, presented *A Family of a Child with Serious Mobility Difficulties; a Mother's Perspective*. Hers was possibly the most moving presentation of the conference which tellingly showed the struggles of a family: the human foibles and weaknesses; a mother's love, disappointments and joys; and a handicapped child's successes. It was very reminiscent of *Betty Peiper's* *Sticks and Stones*.

Rannveig Traustadottir, a conference organizer, made a number of presentations. The one I heard, *Inclusion in Icelandic Schools: Three Case Studies*, which she made with a colleague, *Gretar*

Marinossou, an associate professor with her at the University College of Education in Reikjavik, showed that the problems of integration in Icelandic schools are similar to those that are met elsewhere.

Kathleen Moore of Massachusetts and *David Ferleger*, an attorney in Philadelphia, USA, of Pennhurst fame, presented: *Beyond the Institution: Evolutions in Advocacy Over Twenty Years*, which sensibly presented the limits of litigation for the improvement of life situations of mentally handicapped individuals.

Kristjana Kristiansen made a very forceful presentation on Responsibility and Quality Assurance in a Collapsing Welfare State, which among other things showed the limits of what federal states can achieve. The presentation was highly controversial.

The Panel Discussion: Beyond Normalization, Have We Reached This Point

This panel discussion had earlier been scheduled as a plenary but then became one of the side events as a workshop. We were given a fairly small hall for this presentation and about 100 people had to be turned away because of a lack of space.

Kristjana Kristiansen, *Karl Grunewald*, *Enrique Elissalde* (President of the Latin American Union of the Blind from Uruguay) and yours truly were on the panel and each one of us made a brief presentation on normalization and responded to the theme of the conference: "Beyond Normalization." My responsibility was to report on the May 1994 Ottawa Conference, which I dutifully did (You may receive a copy of the paper I presented by dropping a note c/o the SRV editor).

The most exciting part of the panel presentation for me, was meeting *Dr. Karl Grunewald* of Sweden. *Dr. Grunewald* has a long association with normalization and was one of its first promoters both in Sweden and in North America. Armed with bar- and line-graphs, he showed that over a 20- to 30-year period, with the increased use of community residences in Sweden, the number of mentally retarded persons requiring financial assistance of the state had decreased. He suggested that a whole segment of the population of mentally retarded persons—that is those persons who are mildly retarded—had in a sense disappeared from government scrutiny. It was very good to meet *Dr. Grunewald*. He is a very kind and considerate gentleman. We were all quite taken by him.

Conclusion

If the conference had intended to discuss fully its title theme with the hope of coming to some conclusion, then it was a miserable failure. The conference broke up into factions and by the time the banquet was held, all was irretrievably lost. Thus the conference was not able to create a consensus or direction around the *Standard Rules*. Finally, and this is maybe one of the major disasters of the conference, we were really unable to grapple with the notion of the place of devalued persons in the Third World. A number of individuals noted this but it really wasn't on the agenda of the conference.

On the other hand, the conference allowed me to meet a number of very fine people who share at least a passion to improve the situation of devalued persons in their communities. I also got to visit an incredibly beautiful country and meet some of the most hospitable people I have ever had the honor to meet. I certainly recommend Iceland as a great place to visit; it is truly exotic.

The proper citation for this article according to the American Psychological Association Publication Manual (3rd edition) is:

Lemay, R. (1994). A Reikjavik Journal. SRV-VRS: *The International Social Role Valorization Journal*, 1(2), 42-44.