

## PERSPECTIVES

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### Scandinavian Influences on Intellectual Disability Policy in other Parts of the World<sup>1</sup>

Karl Grunewald

In his first year as President of the United States, John F. Kennedy appointed a national Committee on Mental Retardation. The same year his sister Eunice Shriver wrote to the Danish government, asking for information about the Danish service system for intellectually disabled people. She was later appointed chair of the Kennedy foundation, a position she held for many years. Among other activities this foundation gave an award for research in 'mental retardation'. The background for her letter was the 1959 law that had recently been passed in Denmark. This first contact led to visits to Denmark and Sweden in 1963 from representatives of the President's Committee, a series of visits that became known as "A mission to Scandinavia". That became the start of our contact with the United States.

In their report to President Kennedy, the Committee included the following comments:

1. Both Sweden and Denmark implement policies that pay more attention to the dignity and value of the individual with intellectual disabilities than in the US.
2. Due to the legislation in the two countries, there is a well-coordinated service system, with a continuum starting at birth.
3. The approach is multi-disciplinary, organised in multi-disciplinary, social service teams. Support workers facilitate integration into the community.
4. Small institutions are seen as preferable. Special institutions exist for people with multiple disabilities, and also short-term care (respite), boarding schools for people from rural areas, foster-home placement, and family-care placements.
5. The staff has more responsibility, higher status, better education and higher salaries than in the US.

After this “mission”, many United States experts visited Scandinavia, and several of us also visited the North America. The peak was when Niels Erik Bank-Mikkelsen, Director of intellectual disability services in Denmark, Bengt Nirje, ombudsman of the Swedish parental association and I were asked to write chapters in a book the President's Committee initiated and published in 1969, known as 'Changing Patterns', and edited by Wolfensberger and Kugel. Bank-Mikkelsen wrote about organising services in a large city, I wrote about services in rural areas, and Nirje wrote about the principle of normalisation. The latter was the only contribution with lasting value. The contributions of Bank-Mikkelsen and me were like writing in water, disappearing with the tide, and very quickly outdated.

The second time we had a visit from a United States delegation was in the early 1980s. I had by then written my only scientific article of any value, and had shown that the number of intellectually disabled people in Sweden was about 0.5 %, compared to the 1-3 % figures in the US. Furthermore, only 23% were labelled with a mild intellectual disability in Sweden, compared to 75% in the US. Hot stuff! This was followed by extensive questioning and visits to various schools and institutions. The delegation had a majority consensus that concluded that our low numbers were due to the fact that poverty was virtually nonexistent in Scandinavia. However, a professor who was an expert on testing, argued that the “remaining” intellectually disabled people certainly existed, but were perceived as a part of the normal population. They were simply “undiscovered”, because they had not been tested.

The first international congress on Mental Retardation took place in the United States in 1959. A second was in Vienna in 1961, and a third in Copenhagen in 1964. This latter was Bank-Mikkelsen's initiative, hosted by the Danish National Service for Mental Retardation. There were 800 participants, and it became a break-through for the Danish service system. Visitors found the architecture of the new institutions very interesting. In Denmark, a number of architecture firms had specialised on designing such facilities.

Two years later, a special international congress on architecture for intellectually disabled people was organised, also in Copenhagen. Drawings were studied and copied, and a network was established for future meetings. However, the network faded away in the 1970s. Because by then we had already decided that institutions would not be needed in the future, so that design of a ‘good’ institution was not relevant..

The 1964 Copenhagen congress printed all the lectures in two enormous volumes. The sales potential was however overestimated, and financing of the book project became a headache for Bank-Mikkelsen for several years. Various United States foundations finally helped him out. The contact with these foundations also led to the establishment of a research institute on intellectual disabilities in Denmark, named after Kennedy.

Bank-Mikkelsen became the undisputed ambassador for Scandinavian services. I was following in his wake, but so did many others. Especially pedagogues often

participated, providing information, or with conference presentations. And it was at such events that our reputation for good services was spread. The consequence was that a large number of people visited Denmark and Sweden, even into the 1980s. England even arranged chartered travels.

Bengt Nirje had a special position. His famous description of the principle of normalisation became synonymous with Scandinavian services. It was followed by a number of books on normalisation in North America, England and Japan. Wolfensberger's book on normalization from 1972 is the most well known, but also Robert Perske's books. Seeing people with intellectual disabilities walk winding stairs at a day-centre in Scandinavia (which was prohibited in the US) inspired Perske's famous idea known as "dignity of risk". The term came to be trendy in the US for a number of years, and is still referred to.

Bank-Mikkelsen was a man of clear and drastic utterances. Once he wrote, 'There are two logical ways of treating people: you can either kill them, or treat them with solidarity and respect. I believe in the latter way of treating people'. In 1967 he visited Sonoma State Hospital on the outskirts of San Francisco. There were over 3000 inmates, a large number of whom were children and adults with intellectual disabilities. He saw 50 women gathered in an empty room of concrete. Ten of them were naked. In another unit 90 men were gathered in one single room, with open doors to the toilets. Afterwards he told the US press that in Denmark one would not be allowed to treat cattle like this! There was a reaction all over US. It was strengthened by the fact that Ronald Reagan, then Governor of California, had recently cut the budget for social expenditures. He was forced to adopt a tone of reconciliation at his press conference, but also suggested that the whole situation had been arranged by staff. Some felt that Bank-Mikkelsen had violated the rules of international tactfulness, and the Danish general Commissioner reported home to his government. But on the other hand, Bank-Mikkelsen also received a number of thank-you letters from all over the US.

Two years later I was in a taxi in San Francisco, and the driver asked me, 'Are you the Scandinavian that said we treat people with intellectual disabilities like cattle?'

By the end of the 1960s and into the 70s, Bank-Mikkelsen received a number of invitations to other countries, but had to turn down most of them. At the same time he ran into severe problems at home, because the Danish government let the services for people with intellectual disabilities down. In the mass media the earlier great innovator was now criticised because of scandals at institutions. The sun was setting for the international position of Denmark within this field.

The improvement of services in our Scandinavian countries turned out to be a long process, where the goals were constantly changing as we moved on. But at each point in time, we thought we had sufficient experience to describe a "model"! In the beginning, the models were about the size and organisation of institutions. Some years passed and we realised that we no longer needed institutions for children. But why not also try group homes or guest houses for adults? Five or ten more years passed, and we understood that we did not need institutions for adults

## Perspectives

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either. And the same goes for day-centres for adults. After a number of years, we saw the possibility of better day activities in the community. Now even many of the day-centres are closed, or are considered undesirable.

During this entire process, Nordiska Förbundet för Psykisk Utvecklingshämning (the Nordic Association for Intellectual Disabilities) played a major role. This network was founded at a Nordic congress in Oslo 1963. This association published a periodical for about 25 years. The Nordic countries needed each other. The 1970s and 80s were the decades dedicated to integration. But internationally this did not receive as much attention as the earlier developments. Denmark got stuck half way, perhaps in part because of their new and updated institutions. And Finland was not able to keep up. Norway actually became the most interesting country.

During 1991, integration in Scandinavia was studied by a group of researchers from Massachusetts, headed by Valerie Bradley. They were particularly interested in prerequisites for good services in a highly decentralised system. What were the means of governance, control and quality assurance? They published a very thorough and intelligent report. They are good at theory in the US!

Two persons have spread more information about Scandinavian services to other countries than anyone else, Rosemary and Gunnar Dybwad. They visited Denmark and Sweden for the first time in 1964. At the time, they were employed by Save the Children International for three years to study services for children with intellectual disabilities around the world and to suggest renewal programmes. Rosemary was a sociologist. Gunnar was trained as lawyer and was earlier the director of the US parents society for people with intellectual disabilities for 13 years. After the project with Save the Children, he became a Professor at Brandeis University in Boston, with intellectual disabilities as his speciality. Gunnar died in 2001, Rosemary some years earlier.

The Dybwads gathered tremendous knowledge on services throughout the world, and during the 1960s and 70s they relentlessly referred to the Scandinavian countries as role models. They wrote books, published catalogues, and established scholarships for studies in other countries. Many visitors and scholars came to Scandinavia. The Dybwads were gate-openers for international contact for Scandinavians for many decades. They also had personal links to Scandinavia. The Dybwad family had a mountain summer place, not far from the mountain residence of the Norwegian King. For many years, the Dybwads gathered friends and colleagues at their mountain house.

It was people from the Nordic countries who insisted that UNESCO set up a unit for special education. Two employees from Sweden worked with the Community Based Rehabilitation (CBR) Programmes, a structure of support aimed at implementation in developing country communities. Several people from the Nordic countries have also chaired the international parents association now known as "Inclusion international". I had the honour of being a keynote speaker at their congress in Jerusalem in 1969, with the title "From charity to rights". I repeated

## Perspectives

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the speech the same year for a large audience in Oslo, Norway. The topic was then very “hot” in Norway. The same year “Inclusion International” gathered parents and experts in Stockholm to draft what later became the UN declaration of rights for people with intellectual disabilities.

The Nordic agencies responsible for aid to developing countries are among the few that have addressed disability issues. Among the sister associations, the Norwegian association for people with intellectual disability is the most active in foreign aid. Furthermore, Sweden supports services in North-west Russia and the Baltic countries, including a large project to downsize the largest institution for children with intellectual disabilities in St. Petersburg. Some of our textbooks have been translated into Russian and the Baltic languages.

It is quite suitable to end this presentation by mentioning the person who may be the most famous world-wide expert on disability issues, the United Nations Special Reporter, Bengt Lindquist from Sweden. He has been deeply involved in the UN “standard rules”, and is currently receiving support for the idea that the standard rules should be adopted as some kind of UN Convention.

And so, what are the Scandinavian influences on intellectual disability policy in other parts of the world? From first being known for racial genetics and sterilisations, our countries have progressed to an ideology based on the principle of the equal value of all human beings, and are well on the way toward realisation of such an ideology. To North Americans we are no longer socialist countries with the world’s highest suicide rates. We have shown politicians that intellectual disability is a dynamic state that cannot be met by *the* model or single solution, but rather requires constantly changing services and responses. And the road to full participation and true equality is long, very long. The question is whether the Nordic countries in the future will be able to stand up to their role as model.

### **Note:**

<sup>1</sup> Talk at SORs Nordic Conference April 20th 2002, Oslo, Norway. Extra language help from Hilde Fiva.

### **The Author:**

Karl Grunewald was the Director of the Disability Bureau at the Department of Social Affairs in Sweden, 1961-1986. He is trained in medicine, is a specialist in Child and Adolescent Psychiatry, has honour doctorates, and the title of Professor.