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IN MEMORIAM

Two Swedish men of great importance to the field of disability have passed away in 2006. They are sadly missed, and they and their work will long be remembered by friends and colleagues in Sweden and elsewhere.

Bengt Nirje In Memoriam

After a long period of illness, Bengt Nirje passed away in April 2006. He leaves an international network of friends and colleagues, as well as a closer circle of friends and relatives in Scandinavia, in deep sorrow, but also with gratitude and respect for what he accomplished and for the person he was.

> Making available to all mentally retarded people patterns of life and conditions of everyday living that are as close as possible to the regular circumstances and ways of life in society.

That is the core definition of normalization as defined by Bengt Nirje. It is the most quoted definition of the principle of normalization, and Bengt became internationally well-known for this formulation and his elaboration of it. It was first published in "Changing patterns of residential services", a report from 1969 by a commission appointed by President J. F. Kennedy to look into the living conditions of people with intellectual disabilities, and a milestone for starting the process of de-institutionalization in the US. Since then the principle of normalization has been a worldwide powerful argument and tool in the hands of protagonists for better living conditions for disabled people. Bengt's importance in that respect may be measured by the great number of awards he received. He was, for example, an Honorary Life Member of the Ontario Association for Mentally Retarded, received an Advocacy Leadership Award from Young Adult Institute in New York, and an Australian-European Award from the Australian Government. He was a Fellow of the G. Allen Roeher Institute in Toronto, received a Distinguished Achievement Award for Service from the International Association for the Scientific Study of Intellectual Disabilities (IASSID), and an International Award from the American Association for Mental Retardation (AAMR). He was also made Dr Honoris Causa at the University of Freibourg, Switzerland as well as at the Meiji Gakuin University, Tokyo, Japan.

Bengt was born in Sweden in 1924. He received his undergraduate training at the University of Uppsala, first studying law and social sciences, then philosophy, history of art, cultural anthropology and literature. From 1952 to 1954 he did graduate work in comparative literature at Yale University in the US on a Smith-Mundt Bill scholarship, and at Sorbonne in Paris. He was also active as a cultural journalist and radio correspondent and served at the Swedish institute for international cultural relations.

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This diverse and scholarly background had an impact on the intellectual flexibility and creativity that he showed in his later work with people with disabilities. But perhaps more important for this work were his experiences of working with refugees. After the revolt in Hungary in 1956, the Swedish Red Cross made him responsible for social help and assistance to refugees in camps in Austria and he was later appointed coordinating officer for the United Nations High Commissioners for Refugees (UNHCR). His experiences in the refugee camps had a great impact on his later work. Back in Sweden, Bengt lead a campaign for people with cerebral palsy, which also contributed to an understanding of how degrading and dehumanizing life in total institutions can be, an understanding that heavily influenced his work when he became ombudsman at the Parents' Association for Intellectually Disabled People.

Bengt was one of the first to relate marginalization of people with disabilities to the non-recognition and lack of application of their human rights. The idea of rights can be seen as one of the cornerstones of the principle of normalization. That is possibly also one of the reasons why the principle received so much attention and criticism. Up to that point the discussion about institutions had focused on effects. Defenders of institutions argued that de-institutionalization would have negative effects on the disabled individual, be it his/her cognitive capacities, adaptive behaviour, quality of life or social relationships. Proponents of de-institutionalization and integration, on the other hand, argued that the effects in all these dimensions would rather be positive. The principle of normalization conflicted with these clinical/ therapeutic arguments. Normalization was right, not primarily because of the effect it would have on the individual, but because it was a human right not to be segregated and forced into perverted life patterns and living conditions because of one characteristic. The reference to normal life patterns made it easy for people to understand the situation of disabled people more emphatically, bringing to attention the comparison with lives lead by "us", non-disabled people. At the same time it challenged the clinical perspective and therefore provoked strong reactions. It is probably difficult today, when normalization and its ideological twin concepts, such as participation, inclusion and empowerment, are more or less taken for granted, to understand the heated discussions that took place around this concept in the 1960s and early 1970s.

The principle of normalization has also influenced disability research, and up to the last weeks of his life Bengt kept himself informed of recent research. Most concretely, normalization has been used as a tool for evaluating de-institutionalization. In a project in Uppsala, lead by Lars Kebbon, with Bengt Nirje as a stimulating consultant, alternatives to institutions were evaluated by comparing them with different dimensions of normalization. Internationally the Programme Analysis of Service Systems (PASS) instrument, developed by Wolf Wolfensberger and based on his explication of normalization in terms of social role valorization, has been widely used to the same end.

Much research has also been conducted about the principle of normalization as such, its historical roots, the context that stimulated it and its theoretical and ideological content. Scandinavian researchers have, for example, emphasized its relationship to the Scandinavian welfare model and its egalitarian values. Internationally the Wolfensberger version has been analyzed in relation to the Scandinavian formulations, sometimes explaining the difference as a result of two different welfare models in Scandinavia and the US.

In the critical perspective of disability studies, normalization has also been criticized during the last decade. One of the arguments has been that the principle was not developed by disabled people themselves, but rather should be seen as a professional ideology about what "we" should do with "them". Much in the same line of thought, it has been argued that the principle ignores questions of power and tends to romanticize "normal life patterns" by disregarding the segregation and oppression that disabled people face in "normal" environments.

When confronted with these critical remarks, Bengt showed frustration over what he experienced as a misunderstanding of the normalization principle. He never meant to say that what is statistically normal was always good. Rather, his "normal life patterns" denoted what in a particular culture were seen as good and decent ways of living. Segregation and oppression that violates human rights was in his eyes always wrong, no matter how normal it was in terms of frequency. This frustration over these kinds of misunderstandings often led to an eagerness to discuss, analyze and question the arguments, and he did this in a lively and an enthusiastic way. He was also himself dissatisfied with how the principle was sometimes used by service providers, for example in refusing services with the arguments that such services was not "normal" for other citizens and thus violated the idea of normalization.

Bengt will first and foremost be remembered for his formulation of the principle of normalization. However, he was not only a "thinker", but also a "doer". He worked concretely for de-institutionalization and normalization as a co-ordinator of a mental retardation programme development in Ontario, Canada and later as director of provisions for intellectually disabled people in Uppsala County in Sweden.

Bengt also invested his creativity as a "doer" in the field of sports for people with disabilities in general, and intellectually disabled people in particular. He was the founder of the Swedish Sport Federation for Disabled, through which sports for disabled people broke away from disability organizations and became part of the "ordinary" national Swedish sport organization. He also took the initiative to the first Winter Olympics for Disabled and initiated the International Sport Federation for Persons with Mental Handicaps, in which he served on the board for several years.

His involvement in questions related to disability made him postpone some of the academic projects that he had planned ever since his time as a student. He had documented several interviews he had made with Gunnar Ekelöf, one of Sweden's best-known poets, in order to write about the biographical and contextual background to his poetry. He was also in possession of some unique documentation on the role of Dag Hammarskiöld in releasing Ezra Pound from the mental hospital in the USA where he was placed after the Second World War, and planned also to write a book about that. He never came to realize these plans. However, during his last year of life, he made sure the material would be written about, by contacting people he could trust to write these books in the way he intended to. It gave him great satisfaction to realize that these almost life-long projects would be finished once he himself was gone.

Mårten Söder
Department of Sociology
University of Uppsala

Lars Kebbon In Memoriam

After a period of illness, Lars Kebbon passed away in the spring of 2006. Lars was one of the early pioneers in social research about disability generally, and intellectual disabilities in particular. He was a psychologist by profession, but the importance of his contribution stretches far beyond the limits of his own discipline. He will be remembered for many things, but not least as the founder of the Scandinavian network for researchers, interested in people with intellectual disabilities, that later developed into Nordic Network on Disability Research (NNDR).

Lars started his research career in the field of intellectual disability. His dissertation about measurement of intelligence of severely intellectually disabled people won international recognition. In the 1970s, he worked with a group of young researchers in the so called “MR group” (MR for Mental Retardation), which soon came to be one of the leading research groups in Scandinavia in social and behavioural research about intellectually disabled people. Their longitudinal studies of former patients at a state mental hospital for mildly intellectually disabled people highlighted the negative effects of institutions and the debate about de-institutionalization. These studies were followed by several studies critically examining and evaluating the alternatives (group homes, day activity centres, family support, and leisure activities) to institutions that were being developed. The strategy of evaluation was to deduce from the ideologies of normalization and integration some normative models of what the ideal services should be and compare existing forms with that model. When a lack of congruence appeared (as it almost always did), the process of implementation was analyzed in order to identify critical factors. The strategy was a forerunner to the normatively oriented evaluations that later became common internationally.

The traditional models of evaluation, where the focus is on individual effects, were however not totally abandoned. But they were changed to include broader and more sophisticated criteria that were explicitly related to the goals of services. In a project about “the limits of normalization” in the early 1980s, a multidimensional concept of quality of life was introduced that heralded the development of quality of life research, which later came to dominate international evaluative research in this field.

The majority of members in the "MR group" were psychologists by training, but they preferred to call themselves social psychologists to stress their openness to different perspectives. Up to that point most research into intellectual disability had been done by medical doctors. In relation to that tradition, Lars and his group preferred an open and tolerant attitude instead of confrontation. Intellectual disability, he argued in several articles and lectures, is much too complicated a phenomenon to be monopolized by one discipline. It must be understood from several different angles. Neither a medical, psychological, sociological, social psychological nor an educational perspective can provide sufficient explanations for the problems people with intellectual disabilities face. All the perspectives are needed to help us explain and understand this phenomenon. Instead of confrontation, he preferred cross-disciplinary networking. However, he avoided the term "cross-disciplinary", arguing that it was too ambitious, promising an integration of different perspectives into a single super-perspective. He preferred the term "multi-disciplinary", whereby different perspectives could fertilize each other.

Lars' research focus was later expanded to include people with different disabilities. But, with respect for his empirical research in this broader field, I would say that his most important contribution to general disability research was developing an agenda for, and providing resources to, research. In many committees that he worked on in the 1980s, he never got tired of underlining the need for long-term resources, continuity and quality in disability research. His argumentation was effective and lead to ambitious research programmes from research councils, and one of them was made responsible for co-ordination and further development of disability research.

The centre for disability research at Uppsala University, the first of its kind in Sweden, was established in 1987 at the initiative of Lars, who was also its director for ten years. The development from the "MR group" to this centre illustrates the development from research about intellectually disabled people to a more general interest in the situation of people with different disabilities. The Centre also illustrates Lars' ideas about multi-disciplinarity, its purpose being to provide an arena where researchers from different disciplines can meet, exchange ideas and initiate common projects together. But, and this was of great importance to him, the daily research work should be performed within disciplinary defined departments in order for researchers to keep themselves informed of the frontline research of their own discipline. Disability research, he argued, needs that contact with basic disciplines in order not to wither away.

His own research, as well as his lobbying for structure and resources to disability research, benefited a great deal from Lars' extraordinary talent for building inclusive networks. He dealt with tensions between researchers with different perspectives, between researchers and those being researched, between researcher and practitioners in a most constructive way, using his social talents and emphasizing the common interests of the parties in these conflicts.

His talent for networking also had international implications. As stated above, he formed what today is the NNDR. His broader international network created a bridge for disseminating knowledge about Swedish disability research and disability policy all over the world. This bridge also made it possible for researchers from many different countries to come to Uppsala University. Some came for short visits, others for more extended ones doing, for instance, comparative research.

Disability research in Sweden over the last decade has become established as a legitimate and important field, to a large extent as a result of the work of Lars Kebbon. Many of us who are active in the field today have Lars to thank for our positions and research funds. But we miss and remember him first and foremost as a good friend, who in a most unusual way combined social pleasantness with acumen and creativity.

Mårten Söder
Department of Sociology
University of Uppsala