A Quarter-Century of Normalization and Social Role Valorization

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How I came to formulate the Normalization principle

BENGT NIRJE

In this chapter I will talk about the personal, intellectual, educational, and professional experiences that led me to articulate the principle of Normalization. I have previously discussed this topic elsewhere: in the introduction to the book *The Normalization Principle Papers* (Nirje, 1992) and in the papers *The Normalization Principle—25 Years Later* (Nirje, 1993) and *Basis and Logic of the Normalization Principle* (Nirje, 1985). The written version of the Normalization principle consists only partly of the short paper originally published in *Changing Patterns in Residential Services for the Mentally Retarded* (Nirje, 1969b), on January 10, 1969, in the very last days of the Johnson administration. I say partly because the paper had to be short and I still had more material “in the oven,” so to speak. In fact, the Normalization principle is expressed not only in the first paper from 1969, but also in additional papers written between 1967 and 1972 (which were expressed in summary form in the 1976 edition of *Changing Patterns* [Nirje, 1976]) and in the “rearview mirror” update of 1993 (Nirje, 1993).

1 THE NORMALIZATION PRINCIPLE

At the outset, I think it useful to present a brief summary of the Normalization principle, borrowing liberally from one of my previous papers (Nirje, 1993):

The Normalization principle means that you act right when you make available to all persons with intellectual or other impairments or disabilities those patterns of life and conditions of everyday living that are as close as possible to, or indeed the same as, the regular circumstances and ways of life of their communities and their culture.

The facets or elements of the normal patterns or conditions of life that the principle refers to and which persons with disabilities have equal rights to experience or share are the following:
1. A normal rhythm of the day.
2. A normal rhythm of the week.
3. A normal rhythm of the year.
4. The normal experiences of the life cycle.
5. Normal respect for the individual and the right to self-determination.
6. The normal sexual patterns of their culture.
7. The normal economic patterns and rights of their society.
8. The normal environment patterns and standards in their community.

The proper use of the Normalization principle rests on an understanding of how the normal rhythms, routines, and patterns of life in any culture relate to the development, maturity, and life of disabled persons. It also rests on an understanding of how these patterns apply as indicators of proper human programs, services, and legislation.

The Normalization principle applies to all persons with (for example) intellectual disabilities, whatever the degree of their impairments and wherever they live. It is useful in every society, for all age groups, and can be adapted to individual developments or social changes. Thus, it should
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serve as a guide for medical, educational, psychological, social, legislative, and political work in these fields. Decisions and actions taken according to the principle should turn out more often right than wrong. (pp. 1-2)

Often when studying texts where the Normalization principle is mentioned, I wonder whether the authors really have read any of my writings, including the first one. I cannot blame them, really, because the papers have been difficult to obtain and there was a limit to the number of copies I could distribute to those who were interested. Also, I have never published anything unless I was asked to, and not always then. The papers were always too brief or specific to form a book, or too long or general to be published in magazines or congressional records. Except for my chapter in Changing Patterns—which, I was recently told, was printed in 200,000 copies—and for two magazines and one book, my papers have been samisdats—underground papers for friends, interested colleagues, or students, disseminated to the extent that I had the opportunities or resources to do so. Only two of my papers have been translated into Swedish.

I developed the principle during my work for the Swedish Association for the Developmentally Disturbed (FUB), where, in 1961, I first learned about and experienced the situations of intellectually disabled persons and their families. Thus, I will start with glimpses of the kind of experiences and points of view I brought with me to FUB and that had a bearing on the creation of the principle.

2 STUDIES AND PRELUDES

I will begin with my studies. After my student exam in 1943, I went to Uppsala to study law, perhaps to become a defense lawyer. During those initial years of my studies, which were interrupted in 1944-1945 by my military service, I encountered subjects such as economics and population statistics, the history of law, constitutional and international law, legal philosophy, and ethics. These were the years when the United Nations was founded, the horrors of the war were brought out into the open, and, as a result, we were much concerned with human rights. I also took seminars in philosophy, in which concepts of rights, theories of value, ethics, and the history of philosophy were discussed. I switched from law to what is called practical philosophy, as a stepping-stone to my main interest, literature, and to cultural anthropology.

These first years of study were a great help to me later, in my work with refugees, in my role as the ombudsman of FUB, and in articulating the Normalization principle. I described this evolution in Basis and Logic of the Normalization Principle (Nirje, 1985):

As a former student of law and philosophy, I had once had my own development stimulated by the questions raised by the Uppsala School of Philosophy, by Hägerström and Hedenius [my teacher]. Consequently I knew that concepts of "rights" serve as background for legislation, but also that in some respects, only those conditions which are regulated by specific laws and statutes constitute "rights" in the proper practical legal sense. The rest was called "metaphysical," arbitrary, culture-bound opinions or emotive statements. Human rights consequently involve more than what is actually covered by legislation. Laws can regulate certain conditions for persons with mental handicaps, but they still cannot in a wider sense completely affect the conditions of their existence and their opportunities for personal development. Laws and legislative work cannot provide total answers as to problem solving and proper actions with regard to the realization of human rights. These can only come into existence in the full cultural and human context.

Such problems are not only practical but also ethical, as they relate to what might be right or wrong in making and taking decisions and actions concerning other people. It was apparent that any coherent series of statements on such issues must ultimately be formulated within the demands raised by what in the field of philosophy is called an ethical value theory. Later, that insight was uppermost in my mind in the final work on my first statement of the Normalization principle. (p. 65)

Toward the end of my academic career, I also studied art history, especially architecture (later, I found most institutions to be architectural abominations), and cultural anthropology. I learned about African, Asian, American, and European tribes, their habits, rites, and creations. Ruth Benedict's Patterns of Culture (1934), and her analysis of how the modus operandi in different cultures affected the lives of individuals and their values, made a lasting impression.
During my years of studying comparative literature, my main interest was modern literature and theatre. French, English, American, and, of course, Swedish writers, poets, and dramatists of the 1920s and 1930s offered much to a young man trying to find his way and his views on life. I learned about "life," "reality," and what was "meaningful" from those who were good at expressing and forming images of their experiences and views: Lagerkvist, Martinson, Ekelöf, Lindgren, Ahlin, and Dagerman—great writers whose works are still alive and outstanding. Without a close reading of these writers, listening to their minds, in books or in person, I would not have made the choices I made nor would I have come to the insights that enabled me to find a point of view of my own.

I formed a literary club with some friends which quickly became one of the largest student societies and a place where we could listen to and discuss with the writers of our time. I started to write a little criticism and was also able to take a break from my studies to work as the culture editor for a small but famous anarchist newspaper in Stockholm, well known for its anti-Nazi stand during the war. After almost a year, I was able to return to Uppsala for more advanced studies, preparing a thesis about the early poetry of one of the leading Swedish writers, with roots in French modernist art and poetry.

My studies were modestly supported by lectures on modern Swedish literature that I gave at Folk High Schools or adult education organizations. I also led study groups in the literary club, where we talked about the poetry of figures such as T. S. Eliot. Reading in a group, compared to reading alone, can help one attain richer interpretations and deeper understanding.

Thanks to this experience, I was invited, in 1952, by a professor in Stockholm to take part in an experimental two-week session in group dynamics at an isolated Folk High School near the Norwegian border, with about 20 young scholars from other Swedish universities. The procedure was as follows. Groups of four were assigned tasks to solve and present in writing within 24 hours. Group members were allowed to use the telephone for one hour and the library at all hours. Critical analyses of the work then followed within the group. New groups were formed and the same procedure was followed, for a second and then a third time. The tasks assigned had no relation to our fields of study: My groups dealt, respectively, with how to create a new drainage system in a complex environment, how to reorganize the fire brigades in a large city, and how to present a specific finance plan for the Swedish parliamentary standing committee on finance.

It was stunning how much we could accomplish by working together. We found that we had rarely experienced an "intellectual high" like the one we all felt at the end of the course. Part of the background to this experimental course was provided by new findings in adult education. Many years later, Maja Witting, who was a special-school teacher with strong pedagogical and methodological interests, told me about the ideas of professor Luria in Moscow, as they related to adult education. Apparently, adults learn mainly in a "horizontal" way, from peers, other adults, and their own interests, rather than in a "vertical" way from the teacher "up on the rostrum" to them "down there in their ignorance." This also touched a familiar theme, which was later to become another part of the procedures of the many clubs we would set up. I could draw on these experiences later in my work in a refugee camp and in courses I organized for leaders of clubs in local associations of FUB. People with and without disabilities would participate in these clubs.

Some of the pedagogical insights leading to this approach to group dynamics were furnished by prisoners of war. Some Norwegian professors held in a Nazi prison in Oslo had challenged each other to present short lectures when they had occasions to sit together, as lecturing is what professors normally do. These were later published as the famous "Lectures in Grini." Similarly, British airmen in prisoner-of-war camps had insisted on having their normal five o'clock tea ritual—without cups, tea, or scones—in spite of the guards. Doing normal things in groups in adverse circumstances fortifies the individual, such as leaving the mental institution for a fishing expedition, to take a well-known example. These kinds of lessons I could remember when later faced with situations, in camps or institutions, that offered challenging problems created by the abnormal conditions of life involved.

In 1952, I went to Yale University, in the United States, on a Smith-Mundt scholarship for graduate studies in literary criticism and structural analysis, concentrating on Yeats, Pound, Eliot, Joyce, Hemingway, and Faulkner. A visit to Ezra Pound for an interview gave me my first look at a large American
mental institution, St. Elizabeth's Hospital, in Washington, DC. St. Elizabeth's was a run-down asylum for about 7,000 persons, a city of old red barracks with gray, dusty-looking corridors.

Finally, after some highly stimulating studies at Yale, I went to Paris for half a year of research. I thus learned about American society and French society, as well as the respective languages.

When I returned to Sweden, I found a position with the Swedish Institute that was related to cultural relations with other countries. The job entailed organizing study-visits by foreign university groups, parliamentary committees, and experts wanting an orientation to and information about Swedish education, architecture, industry, and so forth. It was not the administrative systems involved that were important but rather the aims, processes and results within the areas of interest in question. Administrative systems are highly specialized and cannot be copied in the first place. I found this organizational work highly stimulating, with its frequent problem-solving demands, constant meeting of very different personalities, and exchange of specialized information. I was also active as a freelancer, doing radio programs on political and cultural events in the United States and France, including half a year at the United Nations in New York.

Such was my situation in the autumn of 1956. I had had a good Swedish education and had also acquired some international experiences, including foreign languages and academic training. On the other hand, I had no steady job as yet. Also missing were some real-life experiences and a clear sense of where I should apply my skills. I was soon to get answers—in spades, as the saying goes—and my life changed dramatically and decisively.

3 REFUGEES

In November 1956, the Hungarian revolution was crushed by Soviet tanks and troops. Almost 200,000 refugees crossed the border into Austria. Late one evening, I got a telephone call from the secretary-general of the Swedish Red Cross, just back from Vienna, where he had been put in charge of Red Cross services in camps that were being opened quickly. The next morning, I had five minutes to decide whether I would accept a position as a social welfare officer in the first Swedish team being set up. Within a week, it would be in Traiskirchen. I accepted within the time limit. My main instruction was that "your responsibility is the morale of the camp," which could not be allowed to get into the depressing rut of the camps for "old refugees." More than 300,000 of the latter had been living in dilapidated wooden huts or stone barracks since the end of the war. Some of the children born there were almost 10 years old. In time, I was going to meet them.

Traiskirchen, a small town near Baden, south of Vienna, was the seat of an old regiment from the last century, where the emperor's cadets had received their training. Earlier in the year, the last Russian soldiers had left what had served as their headquarters. Their physical demands had been far more than the old buildings could take, to put it diplomatically. By the first of December, the camp already had 3,500 new residents, with 100 to 160 persons per dormitory, sleeping in three-tiered wooden beds. The scene was one of wet snow and rain, loaded buses going to new countries, and more buses entering than leaving. Family members were often missing, and few of the refugees had documents to establish their background or to help locate their relatives or acquaintances abroad. They were people marked by the tragedy behind them and uncertainty about when or where the future would bring them a meaningful life. How was I to create "morale" out of this chaos?

The first need was to find and communicate reliable information on the complicated emigration situation. This task was mostly depressing, because the quotas from receiving countries were filled and increases in the quotas were slow in being established. Still, telling the truth was essential to establish trust and stop rumors. And there were many daily problems and dramas to solve. As a matter of principle, I worked with an open door (if it was not too cold—but then it was warmer with many people present!). Thus, I could be heard giving the same information or assistance to all. When people came with problems, complaints, concerns, or requests, I often asked if they could find others with the same interests and suggested, "Why don't you sit down together and come back with a proposal?" I thus put my group dynamics experience to
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frequent use. Yet the Austrian guards used to ask me: “What are they doing? They should be quiet and grateful, and not hold meetings!” (Later in life, when organizing meetings for persons with intellectual disabilities, I was going to hear the same complaints again. Democratic processes are always a threat to persons in need of complete power.)

But my approach in the camp worked, and that was the main thing. We got a lot of programs going: kindergartens, short dictionaries, language courses, orientation to various countries, sports, watch repairs. People can do many things and have many inner resources, which they need to fight the tedium and the waiting. I learned a lot during those five months in the camp. Then, I was nominated Voluntary Agency Liaison Officer with the Vienna office of the United Nations High Commissioner for Refugees (UNHCR). In this capacity, I also served as a camp inspector, recommending those to be closed first. I also initiated a Scandinavian project, in cooperation with UNHCR and the Austrian authorities, that provided proof of work skills or training opportunities for young people who had no paper credentials attesting to their vocational experience. My cooperation with Swedish labor-market authorities during this project proved beneficial later when we started our sheltered workshops for intellectually disabled people in Sweden.

This period taught me that when you are a refugee, you have a past that is gone and does not count in your new country. No one cares about it, no one believes in it, and nobody trusts you. Your past is really gone, and you really know nothing about the future. Your situation is bleak, uncertain, and anonymous. Such a situation can create a very unhealthy climate and dark moods. I also learned how hard it is to live with so many other persons in close quarters, day and night—100 to 160 per room, week after week after week. It means never having a “private space” for oneself for daily recuperation, satisfying daily activities, or meaningful recreation. There is no place for you, your family, and your few belongings. You have to be strong, even if you are competent and not intellectually disabled. But you can become mentally “wounded” and socially handicapped, of that you can be sure! What keeps you going are your dreams, hopes, and desperate expectations of the future.

4 PEOPLE WITH CEREBRAL PALSY

Back in Sweden, the Red Cross put me in charge of the Folke Bernadotte Action, a fund-raising drive to provide new opportunities for children with cerebral palsy. The aim of the drive was to establish examples of small, homelike conditions instead of hospital settings, improve physiotherapy methods and programs, and to ensure close cooperation with parents, as well as to start a fund encouraging international exchanges and stipends for studies abroad. My work with this fund over a period of several years gave me a good orientation to developments in the field.

A funny thing happened at the first large information meeting held as part of the fund drive. I overheard someone exclaim in a conversation: “And she got so angry that she resigned—the boys wanted to read Hemingway! So now we have no teacher for the evening literature group!” It seems that for years, once a week, a nice elderly lady had held Swedish literature readings for young men with cerebral palsy, 19 to 25 years of age, who were living at home or in one of the two hospitals. So I interfered and offered to take over. And it was, of course, a pleasure. I could lead them in the study of some of Hemingway’s Nick Adams stories and The Old Man and the Sea, discussing the points of view that Hemingway expressed therein, how he worked, and what he meant. For their part, the young men were able to bring me to an understanding of their views on life and of their social and human situation.

Hemingway is a good writer to encounter when you are confronting tough circumstances. He has a matter-of-fact style of great sensibility. He often insists, in the face of difficulty, on the importance of being truthful to one’s own experiences, of being true to oneself, of being able to face oneself with dignity. Hemingway offered fairly strong challenges for young men with cerebral palsy who were trying to come to grips with their lives. And they, in turn, taught me a lot. Talking about literature in a serious way is talking about life. I started to understand how dependent these young men were and how powerless they felt—much as the refugees had felt. They, too, had a past that did not count, an education that they knew was not as good as their peers’, and no solid ground on which to establish a future. Refugees had some hopes and aspirations for
the future, but not these young men. They could not be
certain of where they were going, their present
situation was bleak, and they had very little power.
They enjoyed no independence during the week, and
their weekends were very different from those of other
young people. Their opportunities for dating in regular
ways were nonexistent, and their vacation adventures
were confined to summer camps. Physically, they
could not slam the door and go to a movie, even if their
parents said no. They were dependent, and their state
of dependence humiliated them. From these
experiences, I got my first inkling of the meaning of
independence and the right to self-determination and of
the difficulty of becoming an adult when one is
disabled.

5 MY WORK AS THE FUB OMBUDSMAN

By the time I arrived at FUB in 1961, I had some
education in law, an intellectual attitude, and a
humanistic approach, experience with adult education
and group dynamics, some practice as a journalist and
speaker, familiarity with the ongoing process of
improving Swedish conditions of life, and a
commitment to the United Nations and human rights.
I also had the experience of dealing directly with many
administrative and practical problems that came about
in my position as camp inspector. These personal
attributes and experiences helped me to develop and
interpret my work at FUB and find the threads and
tendencies that allowed me to gradually see and
formulate the Normalization principle. The principle
grew out of my need to understand what to do, and
why, and how best to interpret situations. It also grew
out of other needs: a need for new legislation to correct
the social situation of intellectually disabled persons
and their families; a need for a new approach and a
new language, both nationally and internationally; and
especially a need for a new approach for young and
older adults. I will try to describe these themes one at
time, showing how—especially during the years 1963
to 1966—they influenced the evolving formulation of
the Normalization principle.

In the summer of 1961, I began my service as the
ombudsman for FUB, the Swedish Association for the
Developmentally Disturbed, as it was then called.
When parents formed the first local association in
Stockholm, in 1952, they did not like the official term
"mentally retarded" but preferred "developmentally
disturbed" They thus pioneered the use of this new
term, which was accepted by the law of 1968—which
I will speak of in the next part of this chapter. It is still
in use, but today one generally uses the term
"intellectual disability."

The Swedish Association was formed in 1956, and
I was the first person they employed. My tasks were
the following: to strengthen the development of the
association; to assist in forming a foundation, called
ALÅ, with a sheltered workshop, boarding homes, and
a research council, in Uppsala; to establish interna-
tional relations; and to strengthen the position of FUB
with regard to national and regional authorities. And
all this with a half-time secretary! I chose not to be
called "executive director" or "secretary general," but
simply "ombudsman," for the obvious reason that I
was trying to work and speak in the interests of intel-
lectually disabled persons and their families. It so hap-
pened that some months earlier, Karl Grunewald had
taken up his position at the Royal Medical Board (later
incorporated into the Royal Social Board) as the ins-
pector general of institutions for the mentally retarded.
It turned out to be a lucky coincidence, and we
soon established good cooperation and friendly relations.

With this new phase of my "career"—some friends
called it "another one of your peculiar choices"—I
became an explorer, as it were, in a new, complex, and
paradoxical world, one with hidden tensions and
controversies, great stresses on parents, and pitiful
isolation in institutions for children and adults. It was
a world that functioned differently from the
surrounding, affluent society. I quickly became fully
immersed in it, trying to learn and understand, starting
more or less from scratch, knowing next to nothing
about mental retardation, the developmentally
disturbed, or the social conditions of their parents and
families.

I was neither a parent nor a professional, with no
credentials as a lawyer, psychiatrist, teacher,
psychologist, or social worker, although to some
degree I had had contact with all these fields. To some
extent, I was an information and communications man.
As a person, I found satisfaction in organizing,
problem solving, and getting things changed and new
things going. I had always found that the "make it
new" maxim of modernist poets and writers was an attractive proposal. I liked teamwork, but in these contexts, I was certainly an outsider.

During 1961-1970, I visited most of the Swedish boarding schools, county-based central institutions for children and adults, and the 10 or so state special hospitals, plus many smaller homes. And during these many visits, I listened and talked to staff and—most important—to the residents. I also visited, talked, and listened at meetings and weekend conferences of our local and county associations in every county in Sweden, and at the many courses we organized. Various yearly conferences were also very important, including those of the Swedish Board of Education for deans of special schools, those of the Medical (Social) Board for head doctors of county services and special hospitals, directors of county services (toward the end of my career, I became one of them myself), directors of institutions, and social workers in the services, and those for supervisors of sheltered workshops and leisure-time leaders. There were many issues and problems on the agendas of these meetings, but the Normalization principle was not one of them, although I might have referred to it when taking part in discussions during my very last years as the FUB ombudsman.

During the 1960s, my work consisted of learning and of using new contacts and informational opportunities. I got, of course, rare and extensive insights into the many situations facing persons with intellectual disabilities at the time. This was a privileged education into very sheltered and hidden fields, a special world, as it were. The institutions opened my eyes about the loneliness of the residents and their aimless life, monotonous routines, and drab settings, even though the newly built institutions offered improved environments and more pleasant interiors.

During these years, I also assisted in the development of local associations, which increased from 55 to over 100, and in the founding of 23 county associations, which were needed to obtain regular contact with the county Central Boards for the Care of the Mentally Retarded. The FUB associations eventually operated more than 90 services, including preschool day care, training programs for children without schools, over 20 adult workshops, and more than 25 summer camps. Most of these community programs were later taken over by the central boards, after the new law of 1968 went into effect. I also sat on the boards of a summer home serving children with severe cerebral palsy and intellectual disability and of two homes for blind preschoolers with intellectual impairments, operated with the support of the DBF, the Federation of the Blind, the Red Cross, and the Scouts. During this period, both organizations developed a considerable number of leisure and summer programs for children with various disabilities. The work also involved discussions with authorities on different levels and a lot of information and public-relations work. Having started out with a half-time secretary, I ended up with a staff of over 10. These were dynamic years, during which our budget rose from less than 100,000 Swedish crowns a year to over 1,000,000—and at that time a crown was a crown! And in 1966, we could at last start a magazine of our own.

The following sections will describe in more detail the main spheres of experiences and developments that led to the Normalization principle: the need for and content of new Swedish legislation (particularly the law of 1968); the emphasis on legal aspects and rights, in an international context; the need for new attitudes and new language; and the problems and new possibilities for adults with disabilities.

6 LEGISLATIVE DEVELOPMENTS

The legislation dating from 1954 allowed for institutional services only. Thus, the social circumstances for intellectually disabled persons and their parents were very unsatisfactory and taxing. Writing in 1993, and looking back to the 1950s, I described the situation as follows (Nirje, 1993):

There were no community services for the children, no schools for those who were not considered "educable," no occupation for those who could not work in the open market—sheltered workshops were not intended for them—or on farms for a meagre board and lodging, which was sometimes only a cover for humiliating serfdom. There were no family services to speak of and no leisure-time arrangements, except for a few small summer programs run by the FUB local associations.

If the parents could not cope, the responses were institutions—central boarding schools for children, or central county institutions or care homes for
children or adults, or state special hospitals for those with profound or severe, complicated, or additional disabilities, or work homes for adults, privately or county run, mostly separate for men and women. The institutions very often used large dormitories (for up to 8-12 persons) and had very limited activity programs, giving depressing impressions not only to the parents, who were faced with hard and fateful choices. Sometimes the conditions were horrifying and scandalous. (pp. 2-3)

For Swedish parents, the institutions were bleak residences. But visitors from abroad, including the members of one of President Kennedy’s committees in 1962 and others who followed in their and Gunnar Dybwad’s footsteps, were shocked for quite different reasons: They thought that the modern Swedish facilities were small and nice, compared to their huge and horrible institutions! They had difficulty in understanding why we were criticizing the new institutions, which looked almost like modern suburban row housing. But the reality was that we did not like their implied segregation and their lack of programs. They were still not homes. Swedish parents wanted other choices and opportunities and more human contact. And there were still very few alternatives to institutions, only a few of which were new, although many more were on the drawing boards. So, the choice for parents was often between the unthinkable and the impossible.

The 1954 Swedish legislation thus did not offer much in terms of services in the community. Various demands and shifting views were discussed within FUB by groups that each had a different focus, although all were cautious, apprehensive and dissatisfied. My job was to coordinate these differing views, which I did by bringing forward all the positive proposals as new legal texts or as new paragraphs in the existing law. This turned out to present an understandable alternative. From then on, we were able to meet regularly with a four-member committee, of which Karl Grunewald and Lennart Wessman, the inspector of special schools in the Royal Board of Education, were significant members. The views of FUB were shared by the committee, and their basic proposal for a new law was presented at the FUB biannual general assembly in 1964. Later on, their final proposal was sent out to all concerned political and administrative bodies—the regular way of handling important legislative matters in Sweden—and was very favorably received. This led to the final bill, which was passed by the Swedish Parliament in December 1967. The law was no longer centered on institutions but rather on the legal right of developmentally disabled persons to services in the community. Education and meaningful occupation now became obligatory, with community services to include education for all children, small pupils’ homes, and group homes and occupation centres for adults. Administrative responsibilities still remained with the 23 county parliaments.

The point I want to stress here is that these main legislative demands and efforts, presented by FUB in 1962-1963, were made well before the first conscious expressions of the Normalization principle. These legislative concerns and directions were thus a prerequisite for my formulation of the principle, a process that took place during 1963-1967.

Every fourth year the Nordic professional associations hold a congress, and in 1963 I was asked to present the parents’ views on institutions. I was therefore invited to Denmark to see some of their institutions. There, I got to know Niels Erik Bank-Mikkelsen, the dynamic leader of state services for the mentally retarded. In his office, reading the preamble to the Danish Law of 1959, for which he had been the driving force, I found—and later helped to make famous—the words expressing the fact that the aim of the law was “to let the mentally retarded obtain an existence as close to the normal as possible.” This law preceded the Swedish law by almost a decade. Still, the Danish institutions were larger and often had much bigger dormitories than those in Sweden. At the Oslo conference in 1963, where we took part in the special session on institutions, I presented the criticism of the institutional conditions in our countries, with some sharp examples, especially from Denmark, where conditions were not “as close to the normal as possible,” here using the quote for the first time. The other participants did not altogether share our views, and some parents were upset with mine. Bank-Mikkelsen, however, was very cheered by them and found them helpful. Our presentations were then published by a small Swedish professional magazine. One can see that none of us were ready yet to talk about “Normalization,” much less about a ‘principle.’” Its time had not yet come.
There was interest at the time in the legal aspect of services, which also had an international aspect. In 1963, the cooperation of parent associations within a European League was widened into an International League, with the chairman of FUB, John Philipson, a parent, as the new president. He was a medical doctor and vice-chairman of the Swedish Red Cross, whom I had met in my refugee work in Austria. He was warm, diplomatically skilled, and internationally experienced. He brought me in to assist in his new tasks. One of the things the International League promoted was exchange of information on legal developments. The Scandinavian experiences were of great interest to many.

This led to the Stockholm Symposium of the International League on Legislative Aspects of Mental Retardation, in 1967. This gathering, of which I was the organizer and one of 30 participants, was masterfully led by Richard Sterner. It included active representatives from Great Britain, Ireland, the United States, France, Switzerland, Spain, and the Nordic countries. Niels Erik Bank-Mikkelsen, Lennart Wessman, and Karl Grunewald acted as experts. The symposium was a landmark for the League. I can still remember the happy atmosphere of accomplishment and satisfaction as we realized that we had put together something quite important and internationally significant.

Students analyzing the statements of the symposium will not only find the words “normal conditions” a few times. They will also recognize the main themes in the statements, including their human rights base. The Stockholm symposium led the International League to adopt the motto “From Charity to Rights” for their Jerusalem Congress in 1968 and to use the work as a basis for the Jerusalem Declaration of the Rights of the Mentally Handicapped. This, in turn, through French efforts, was brought to the United Nations, where it led to the United Nations Declaration on the Rights of the Mentally Handicapped in 1971. This was followed by the United Nations Declaration of the Rights of the Disabled in 1975. In both of these UN documents, the word “normal” can be found.

However, at the Stockholm symposium in 1967, the Normalization principle was not yet written and thus not known to the participants, even though I had presented it in lectures in the United States at the beginning of the year. At the symposium, I used slides to present my views on institutions. In doing so, I was supported by Bank-Mikkelsen, who had just returned from his visit to the United States and, specifically, California. This was the visit that had so upset Governor Reagan and cost Leo Lippman his job. During his visit, Bank-Mikkelsen made his famous comment, “In Denmark, we treat cows better than you treat people in your institutions.”

Looking back at the conclusions of the 1967 Stockholm symposium, these specific views of Bank-Mikkelsen and mine are not to be found therein. The written sections, representing an international perspective, express very modest proposals, reflecting the helplessness that many felt in the face of the authoritarian systems that lay behind the austere facades of the large institutions, which were the main societal option at the time. Proposals were made for improved staff education, for stimulating training programs, for placing new smaller institutions nearer the communities, and for providing more day programs in the community, for better contact. Much importance was placed on safeguards such as guardianship and parental participation in decisions. The conclusions reflect a distrustful, cautious, and overprotective approach—from today’s vantage point, which says a lot about the changes that have taken place during the last three decades! It was a very representative and competent group of parent association leaders behind the conclusions. In parentheses at the end of some sections—but only in parentheses!—the more advanced experiences from Scandinavian countries were mentioned, describing smaller-sized institutions and dormitories, and forums for parental influence.

7 SOME PROFILES: BANK-MIKKELSEN, GRUNEWALD, AND WESSMAN

The major trends of the time were directed toward the establishment, through legislation, of reliable social services in the community instead of institutions. No parent—whether in Belgium, Spain, France, Ireland, the United States, or Sweden—wanted to place their sons or daughters in these institutions. They were given no other alternative, however. The urgency felt for such alternatives was the driving force behind the Nordic parent associations. Their situation was made
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easier by the fact that these views were expressed by professional leaders, who, in their administrative capacities, were able to lead developments in the desired directions: Niels Erik Bank-Mikkelsen in Denmark, and Karl Grunewald and Lennart Wessman in Sweden. They all enacted their roles with gusto.

After his work as a journalist in the resistance movement during the war, and imprisonment when caught by the German occupiers, Niels Erik Bank-Mikkelsen became a lawyer. He got his first job as the temporary director of the section for mental retardation in the Ministry of Social Affairs. He never left that job. In Denmark, the institutions were administered by the state. Being densely populated, the country had made them large to accommodate their few regions. In the 1960s, he worked on reorganizing the inner structures of the institutions. The doctors were no longer solely in charge but, rather, had to collaborate with psychologists, social workers, and administrators. Bank-Mikkelsen cooperated with the parent association in establishing sheltered workshops and group homes in the community. He had also established a special institute of higher learning for staff training. He was a strong advocate for the civil rights of the mentally retarded and had the courage and the standing to be the harshest critic of the institutional situation. His main view of Normalization, when that word began to come into use, was that it meant a home to live in, a job to go to, the same leisure time and civil rights as were enjoyed by others, and services that were the responsibility of communities, not the state.

I met him in 1963 and heard him at congresses, and we became friends. Especially after Changing Patterns, we sometimes made presentations on the same occasions. He was inspirational, a fighter, and a warm humanist.

Karl Grunewald was a child psychiatrist who, in 1961, became the inspector general of the institutions. These were run mainly by the counties, but there were also some special hospitals operated by the state and a large number of smaller institutions or privately operated “homes.” As Sweden was sparsely populated, the counties had smaller institutions, with those for children being mostly separate. Two state and two county institutions held more than 500 residents. Grunewald’s office often severely criticized the conditions encountered. But he also stimulated new activities and programs in these institutions and fought against doctors’ advising parents to place newborns with Down’s syndrome in institutions. He also spoke out against the practice of sterilization. Like Bank-Mikkelsen, he was very active on the architectural side when it came to approving new facilities, working for more homelike and normal environments. He recommended very strongly his “small group principle” when organizing life in institutions or in the community. He enjoyed writing and was also an inspirational and creative programmer of the many annual conferences for the various groups of professionals. Bank-Mikkelsen was in charge of the Danish institutions, and Grunewald was the sharp inspector of county services in Sweden. Although their roles were different, they shared the same approach toward community services. As the FUB ombudsman, I worked very closely and enjoyably with Grunewald.

I often knew about his inspection reports in advance and could prepare the FUB people in the county concerned. Thus, when the reports were made public, together, we pressured the counties to improve standards and services.

Lennart Wessman, Karl Grunewald and I were often involved in the same causes, and we were sometimes called the three musketeers by friend and foe. Wessman was the inspector of special schools, fighting boarding schools, which he found detrimental to the work of education, increasing and improving classes for the trainable, and all the while pressing for integration within the regular school system. He strongly promoted work education and work training. With his interpretation of the law of 1967, he could at last make sure that all children had educational rights, including the most profoundly disabled.

I discussed problems with Grunewald and Wessman that I learned about from the local associations or had noted myself. We talked about desirable changes in regulations, future changes, or issues for the conferences, where I always presented current views from FUB and international news. We rarely had time to talk about “philosophy”—there was no need to do so, as we readily found that we shared the same humanistic views. Such talks happened more frequently after I had written the Normalization principle. I no doubt mentioned themes from the principle in talks about conditions with county deans or directors of institutions or homes.
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8 ROADS TO “NORMAL”

During the visits mentioned above, I always tried to find time for quiet talks with residents, if they were able to speak. Most of the time, their language had not been developed in stimulating environments, with the silence of the wards a recurring experience—unless the radio or, later, the TV on. They told me about their boredom and tedium, how they understood their parents’ earlier problems because of them, and how they realized that they would never get the opportunity to leave the institution. The boarding-school pupils sometimes spoke about the envy they felt toward their siblings, who had so much more exciting leisure times.

In the early 1960s, I had the opportunity to see a series of five documentaries from the British Mental Health Society, where a hidden camera followed the reactions of five small children, all under the age of 3 (6, 12, 18, 24, and 30 months old), who had been separated from their mothers for a longer than usual but still brief period. They were not disabled and were taken care of in the very best way. Still, it was horrifying to follow the children’s withdrawal, anxiety, regression, and aggression during and after separation from their mothers. These films informed me of the undoubted impact on children with disabilities, who are placed in institutions soon after birth and never allowed to experience creative relationships with their parents, from the very beginning. They were bereft even of their past. Such an existence was debilitating and abnormal, no matter what the doctors said.

I was struck by the fact that so many families cared for children who were far more impaired than those I found in the wards for multidisabled children. I was also struck that many of the children, young adults, or adults I met in the community were as impaired as those I met in the institutions. It was thus evident that an isolated institution could not be the only option. Growing up in the community offered more stimulating experiences to learn from, provided a better feeling of security, and offered more joy and family connections. As a matter of fact, more persons with intellectual disabilities were living in the community, even though the services there were negligible and cost the counties little or nothing. Nevertheless, the counties were planning new, modern institutions. I found that the developmentally disturbed had their development additionally disturbed by institutional environments that did not allow them to learn and grow from experiences of the so-called “normal” world. Certainly, the institutions and special homes were not “normal.” Rather, they were often scary and abnormal, unsuitable for their complicated developmental purposes. The situations were not socially normal in either the institutions or the communities where the families lived.

On the other hand, so much was in the works, including making institutional environments more “normal” and creating new services in the community to diminish the demand for institutional placements and to make possible more “normal” social situations. In the atmosphere of the progressive 1960s, it was in the air to improve the lives of people with disabilities, to allow them at last to share in the increase in the social capacities of their communities and countries. There were sufficient and sometimes appalling reasons to make this a necessity.

In explaining the Swedish approach to architecture or social services, we often used the expression, “It is normal to have a room of one’s own.” Especially if one is profoundly impaired, a ward for 10 or 20 or 50 or 100 is not an environment that can be understood. With a room of one’s own and a normal home environment, on the other hand, it was easier for people with disabilities to understand and to acquire the skills needed to manage personal issues such as using the toilet, dressing, or eating—in a word, the activities of normal daily life, ADL. This was a better way of talking and dealing with the facts of life of disabled persons, rather than merely comparing systems.

I had found that wide variations in national patterns of legislating, implementing laws, delivering services, and establishing regulations were expressions of different administrative cultures. These variations often prevented us from efficiently exchanging experiences, insights, strivings, remedies, aims, or solutions. The reason was that basic meanings and patterns of life, according to which persons with disabilities and their families lived each day, were not communicated in understandable and relevant ways. More and more, I felt it urgent to find a common language. I also felt that the word “normal” was a key to the needed language of mutual understanding. I had often used it in my own talks and presentations to various groups, as well as in discussions.
During the 1963-1966 period, I began to use a pedagogical device in my talks to nurses, social workers, parents, or the general public, including politicians. I described a normal day, week, or vacation for a typical individual or family and then contrasted these with the days, weeks, or vacations experienced by intellectually impaired children, adolescents, or adults and their families. In this way, I was able to show what needed to be done to make the situation of the latter more normal and less handicapped. I found this point of view made it easier to analyze the components of problems and recommend priorities for action. From these contrasting perspectives, it was also easier to analyze the situations of persons with intellectual disabilities living in institutions.

I reached an understanding of the components of my principle during those years through observation and analysis. The Normalization principle is an inductive theory, rather than a deductive one to be imposed from above, as I have often had reason to explain. I gradually saw an underlying coherence in my observations and analyses, such that I started to call this coherence a "principle." This also made it possible to define its logical structure.

The origins of the perspectives underlying the principle of Normalization were not rooted merely in demands for rights that were to be attained through new legislation, nor in tools for describing problems and solutions on an international level. These perspectives also stemmed from the point of view of people with intellectual disabilities themselves.

9 TOWARD INDEPENDENCE

I had become acquainted with the views of people with intellectual disabilities from listening to them in homes, institutions, leisure-time clubs, and sport training sessions. The FUB leisure-time clubs were started to create more meaningful and entertaining leisure opportunities for the "children," who, in fact, were mostly young adults. Since 1962, I had been a member of the advisory committee for sports for people with disabilities and helped to start FUB sport groups. During the summers of 1962 and 1963, I assisted Daniel Melin, a legendary pastor, special school dean, and mentor for FUB developments, as well as my predecessor as the executive member of the FUB board and the "father" of many associations. I helped him run confirmation sessions for those who, because of their intellectual disabilities, had not been accepted for these initiation rites by the officials of the Swedish church. (A protest letter to the Swedish bishops later changed this situation.) During these pleasant summer weeks, my job—being a heathen—was to take care of sporting activities, leisure time, and excursions. It was very educational, especially for me.

My first visit to Denmark in mid-summer 1963 included a planned meeting with staff and workers at a sheltered workshop. For technical reasons, their place of vacation had suddenly been changed, so I had to meet them at the famous Askov Folk High School, started by the legendary theologian Grundtvig in 1844. The first Swedish school of this kind opened in 1868. Since then, several hundred such "People's Colleges" have been founded in the Nordic countries by organizations, churches, parties, and counties. There, adults with limited formal education who wanted to learn new things and improve their lives could do so, thereby preparing themselves for a better and more active community life. In these boarding schools, people could study, for a year or two, what they were highly motivated to learn. They also had opportunities to talk about life and what they wanted from it with new acquaintances who had similar interests. Toward the end of the last century, the Folk High Schools became cradles for democratic movements and processes in the Nordic countries. This Danish group, however, only used the school as a hotel between excursions. But they were intrigued by the new environment, as I found out when, in the evening, I helped them enter and explore some of the new buildings, which contained laboratories, music rooms, and a library, and had geography and history maps on the walls. Afterward, on a little hill below a giant tree, we had a memorable talk about why adults still wanted to go to school. Even if going to school was not always a pleasant experience, it was easy to understand that anyone could profit from learning how to handle money better, or vote, or travel. I was also struck by the need to create teaching methods to make such learning possible.
Later that year, I met Elliot Avedon, who was a professor of recreation—an unheard-of subject in Sweden at that time—at Columbia University in New York City. On the recommendation of his older colleague Ignacy Goldberg, Avedon visited Stockholm, where I described the Swedish “mental retardation” scene. He gave me his book on the social training of persons with intellectual disabilities, which had been used in leisure-time programs in New York since the end of the 1950s. The book was valuable in describing a three-step approach, to which we later added a fourth step, through the experiences and developments of our clubs, the step being a report about having made a decision on one’s own and carrying it out. Such reports became more and more frequent, suggesting increased social contacts and participation, independence, and self-determination.

In 1964, I wanted to organize a two-week summer course in social training but was turned down by my board. Later, at a conference for the Swedish deans of special schools in 1963 or 1964, when I pointed out the necessity of developing adult-education methods and opening Folk High Schools for persons with intellectual disabilities, people just shook their heads. One of the leading deans came up to me and said: “You are really funny. I’ll bet that next year you’ll stand up here and say that they should have an entrance exam and be able to go to Uppsala University, just like yourself!” Happily, I was going to get the last laugh before long.

In 1965, Daniel Melin saw to it that I got funding for my two-week social-training course, under the guise of a reunion for some of his “pupils” who knew me from the previous summers. I had questioned the young people’s parents about their children’s social skills, special habits, likes, and dislikes. In a setting like a Folk High School, we could also use small cities as venues in which more and more complicated and challenging tasks were presented to groups of two, one girl and one boy, who were accompanied by an assistant teacher. The course taught the participants some new skills and improved others. We also found, however, that they had skills that their parents did not believe they had or had never seen. Friends in this group later that year formed the first club. My assistant in the course was Ann Bakk. She was a young journalist and, later, a psychologist and writer. She also became the driving force in the creation of clubs and courses for club members. Half were “camouflaged” assistants who, in reality, were often friends of ours. These courses took place on weekends. The subject was “how to be a tourist.” Later, I called it my “attitude-changing machine.” I always achieved the same, predictable result with it, although the result was surprising for some, including a few times in the United States and in an institution in Canada (the director of which was a former Hungarian). There were eight pairs of persons with intellectual disabilities and eight pairs of persons without disabilities, each composed of one man and one woman. Every pair met three pairs from the other groups, persons they had never seen before, much as a tourist meets new people. I had based the three components of the course on my interpretation of “mental retardation” as consisting of, first, the individual cognitive impairment, second, the disability in learning, and third, the awareness of being handicapped. With the help of some funding to cover the costs of practical problem solving, meals, transportation, and amusements, the course consisted of a short introduction where participants found out that they were in a group with an unknown person and were going to meet a lot of new people. They did so while exploring the city, having lunch and dinner, experiencing fun in the evening, and having a Sunday-morning constitutional, followed by lunch. At the end of each session, the “assistants” were debriefed. The persons with intellectual disabilities had their own evaluation discussion at the end of the workshop, after which they presented their findings and views to the others. As the wheels of the attitude-changing machine came to this final turn, the other participants came to realize that the real teachers at the workshop were the people with disabilities.

The clubs and workshops gave rise to some 40 clubs within a few years. This led to courses in parliamentary rules and procedures, to enable the young people to run their own clubs, hold elections, be board members, plan programs, and make their own decisions about leisure-time and other activities (e.g., putting on their own conference with members of other clubs to discuss issues of mutual interest). The first such conference took place in May 1968, with 20 participants. The starting point for us was always the wishes and self-expressed needs of the young adults themselves. Their interests and motivation were the main driving force. Being in groups developed their
strengths and abilities, as well as their confidence to do things on their own.

The “fourth step,” as we called it, was achieved by members when they called up a friend to go to a movie or went to a museum or event on their own. The loneliness of the young adults was a great concern for their parents and thus these peer-group models, whom participants found in the club, were very important. Our experience taught us over and over again that parents, because of anxiety, often underestimated or were unaware of the skills and competencies that their children possessed. The young adults often mentioned that they were sad because they understood how sad their parents were because of their disability. The young adults also often wanted a life in which they would be on their own, like their older siblings. They wanted to learn how to handle themselves and be as independent as possible, by learning how to vote, cook, speak English, use a bank, and so forth. The clubs made them feel stronger, and the conferences gave them a voice. They began to be heard and respected on their own, for themselves. Their disabilities were not unknown to them, although their future was, despite their having often hidden hopes. It was really important for them to become adult, be respected, be seen and understood, and have the same right to self-determination as everyone else.

The common concerns of the leading organizations for people with disabilities, including those who were blind, deaf, or physically disabled, were for social improvements, such as better labor-market opportunities, transportation, and technical aids for use in the home, on the job, or in the community. In 1963, the perspectives and goals of these organizations were widened due to increased pressure from the parent associations for persons with cerebral palsy or intellectual disabilities. I was much involved in this development. The Handicap Associations Central Committee (HCK) was formed, which led to new strengths. Opportunities for persons with cerebral palsy or intellectual disabilities were also strengthened, because their interests were now articulated from within a wider perspective and were advocated from a larger platform.

In 1965, the Swedish Board of Education asked HCK to appoint a committee of three to prepare ideas and rationales for wider cultural opportunities for persons with disabilities. I was one of the three committee members. We recommended things such as sign-language dictionaries and expanded interpreter training to serve deaf people, and more and better Folk High School opportunities for persons who were blind, deaf, physically disabled, or intellectually disabled. I was also able to recommend the development of adult-education methods and materials for evening study-circles, such as adult “easy readers” (i.e., shorter versions of classic and modern literature, in language suited to the needs of intellectually disabled persons). Our proposals were accepted the following year by the Riksdag, the Swedish Parliament, to the surprise and consternation of FUB, which at the time did not consider these matters very important. These ideas were all new and untested.

New developments and dynamics started, which rather quickly turned into new centers for activities. Today, more than 4,000 persons with intellectual disabilities have studied at year-long Folk High School courses, and about half of all intellectually disabled adults have taken part in study circles. Also, more than 300 “easy readers” have been published and can be found in public libraries. A weekly magazine and easy-to-read public information are available as well.

I was heavily involved in and often the initiator of these new endeavors (e.g., as a member of the committees for adult-education circles and “easy readers,” beginning in 1966), which played a significant role in my later articulation of the Normalization principle. They added to the feeling of urgency regarding the rights of young adults with intellectual disabilities, including the right to have opportunities for “higher education” equivalent to those enjoyed by other adults, to have a voice and social situation appropriate to their status as adult citizens, and to have the right to grow, develop, mature, and attain self-determination. This emphasis on the importance and meaning of adulthood is the most “revolutionary” part of the Normalization principle.

The first conference for persons with intellectual disabilities took place in mid-May 1968, concurrently with the biannual assembly of FUB. At the end of the last assembly session, the young adults presented their report—it must have been the first time in history that such a parent assembly received a report from “their children.” The conference for these 20 persons was a great success. By the use of group dynamics and
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democratic procedures, we had assisted the intellectually disabled to "make it new"—to create something that had not existed before; a new content in an old form, a new form for an old human content. Not everyone was pleased with these developments, as I will recount further on.

Two weeks later, I left for the United States to write a paper on U.S. institutions, at last. It had not been easy to go there, but the pressure and means to do so had presented themselves. How all that happened is the next act in this story.

10 INTERNATIONAL DYNAMICS

Before going on with the actual writing of the Normalization principle, I think it important to set the stage by recounting some of the trends that were present and influential in those years. In the field of mental retardation, the 1960s were characterized by the many endeavors of concerned parents and professionals to find one another within and across borders, to learn, to exchange experiences and, above all, to search for new solutions, new ways, and new approaches. The European League became the International League of Societies for the Mentally Handicapped in 1963, and the International Association for the Scientific Study of Mental Deficiency (IASSMD) was formed in 1964. Previously, President John F. Kennedy had appointed a President's Panel on Mental Retardation, which, in 1962, sent study groups around the world. One group came to Denmark and Sweden, where FUB and Karl Grunewald were much involved in the visit. Harvey Stevens, commissioner of mental retardation for the state of Wisconsin, was one of the participants and in 1964, he became the first president of the IASSMD.

In 1963, Gunnar Dybwad left his position as executive director of the U.S. National Association for Retarded Children (NARC) to work in Geneva, Switzerland, for the international Save the Children organization as an adviser on mental retardation. Gunnar and Rosemary Dybwad formed a remarkably dynamic couple who, for decades as benevolent spiders, built a strong web that connected people and ideas around the world. When they left the US, a scholarship fund was raised in Rosemary's honor, which sent study visitors to places of special interest. Almost all of the first recipients made the Grand Tour to Copenhagen, Stockholm, and Oslo.

One of the reasons FUB hired me was to acquire more international information. In 1961, for the first time, in London and The Hague, we met persons from other national parent associations. FUB was particularly interested in obtaining information on sheltered workshops, which is why the second part of the conference—the Dutch part—was the most interesting. At that time, sheltered workshops were a new idea for Sweden, where up until then such services were not intended for persons with an intellectual disability. The man behind this new approach was Bengt Junker, an industrial economist, who as chairman of the Swedish Boy Scouts had led the Folke Bernadotte Drive for Cerebral Palsy. He had asked me to take on the job as executive director of FUB to, among other things, start the ALA Foundation for a pilot workshop project. His wife, Karin Stensland-Junker, vice-chairman of FUB, was the one who guided me on my first tours to meet some of the children with the most complicated or profound impairments and to see institutional settings that were not always up to par. She invented the “lekotek” (toy library), an ingenious solution that offered mothers advice for the stimulation of their impaired child during their early years, with toys from the library at their disposal. The first lekotek was in the room next to my office, where I did most of my work. Her lekotek later proved to be an idea for export.

Our main concern was to import the sheltered workshop idea from the Netherlands. The president of the European League was Mr. van Daym, the director of the workshops in The Hague. In these years, papers presented by Speijer, Wehrmeier, and Meuzelaar were important events, and I was also sent to visit their workshops, as well as others. My translations of their papers formed a substantial part of the lectures I gave as part of the instructional courses offered by the Swedish Labour Market Board to the foremen of the new workshops for the developmentally disabled. These were mushrooming in the mid-1960s due to the work by FUB, much to the irritation of county authorities. But in our association we had fathers who were competent in a number of trades and who found great satisfaction in these new opportunities for their young adults.
At that time, in London, we heard and saw Jack Tizard’s presentation of the Brooklands “experiment,” in which multidisabled children were given a special child-stimulation program that was very similar to those that had started in Sweden. Later, we succeeded in showing the program on Swedish TV, and I served as a translator and speaker. In Brussels, in 1963, Ignacy Goldberg, from the US, was one of the main speakers. He continued on to Sweden with his lectures on preschool education and, as his interpreter, I learned a great deal on the subject.

Many other new developments were presented at such conferences, which provided many stimulating exchanges. In 1966, Herbert Gunzburg, a psychologist from England and the editor of the British Journal of Mental Subnormality, presented his system for assessing social capacities. At the same congress of the International League in the UNESCO building in Paris, professor Henry Cobb of the US gave a fascinating presentation on The Attitude of the Retarded Person Towards Himself (Cobb, 1967). That paper helped me to underline some important statements at the end of my first paper on the Normalization principle. Henry Cobb and Ignacy Goldberg were invited by John Philipson to a memorable lunch at the restaurant in Brussels that had served as an important place for the Belgian resistance movement. This was Ignacy Goldberg’s first visit to Europe after he had left Poland at the beginning of World War II, when he joined the Polish troops in the British army and was later severely wounded at El Alamein. Ignacy, Henry, John, and I found each other talking the same language when we discussed the necessity of changing the European League into an International League, to strengthen international cooperation and exchanges of ideas and experiences. Henry Cobb later followed John Philipson as president of the International League. International dynamics were thus very strong in the 1960s, and I would be remiss if I did not mention that Niels Erik Bank-Mikkelsen and Karl Grunewald played leadership roles and were often heard abroad at many of these congresses.

There were also many transatlantic exchanges, with a considerable influx of American visitors to Scandinavia and return invitations for some of us to visit the US to present our views. G. F. Jerry Walsh, the executive director of the Minnesota ARC and the initial Rosemary Dybwad award recipient, was the person who first invited me to visit the US. I had met him when he visited Scandinavia in 1966. As I relate later, he came to play a significant role in my life in the creation not only of the Normalization principle but also of “the right to self-determination” and the setting up of the International Association of Sports for the Mentally Handicapped. He has been a promoter, guide, and friend for more than 30 years. He was also a Marine Corps veteran who served in the war in the Pacific in Guadalcanal, Tarawa, and Saipan. After the war, he received a B.A. and M.S. in business administration from the University of Minnesota. He was the first executive officer of the first state Association for Retarded Children (ARC) in the United States, and was later the first of the Rosemary Dybwad explorers.

In April 1966, around Easter time, Jerry met with experts and visited institutions in and around Stockholm. He stayed in my home, which gave us much time to talk. I was able to show him a brand-new institution for 450 persons, featuring small apartment houses with single and double rooms grouped together in the form of a modern village, with a piazza, restaurant, barbershop, shop, and café. The institution was located in pleasant, hilly terrain that overlooked the rivulet that meandered across the village. It was so new that only the very first residents had moved in. That Good Friday, the institution was deserted. At the end of the visit, when I showed him one of the houses for multidisabled persons, with all the new technical aids, I turned to find that Jerry had disappeared. After a while, I found him in a bathroom, wiping his eyes. He burst out: “Here you are, telling me about all the things that are wrong with this place—that it is far too big, that it should not be here but in a community, and that it should really not exist at all—but I will never in my life be able to see anything as nice and good in my country!” And then he started to tell me about American institutions. Thus began our friendship, which would lead to so many more developments and meetings.

11 THE U.S. INVOLVEMENT

Upon his return, Jerry Walsh presented his European observations to the annual convention of the Minnesota ARC, on June 10, 1966, in Duluth. He quoted us as having the following exchange: “The philosophy I found can best be expressed thus: The
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key, then, is trying to achieve the same good standards of life for those retarded children as you want for people who live in general society?" I responded: "Yes, our aim is to create such facilities, and we are far from it. Our aim is to make conditions of life as similar or the same as for the rest of the population. You have to do it for human dignity and human decency." And later I added: "We in the Swedish Parents Association want the institutions not to be institutions at all. Rather, the conditions there should be as homelike as possible, not too different from the situation in a private home. In that way you can have a continuum of existence in the family home and in the care home, and you would not be alien in any place."

After commenting on the high quality of staff members compared to those found in American institutions, the efficient inspection services, and the fact that service financing was in addition to pensions for all disabled persons (regardless of whether they lived in institutions or in the community), all of which contributed to the high Swedish standards, Jerry Walsh shared with his audience the impact the study tour had made on him: "It's truly amazing and almost unbelievable that a few thousand miles away, 10 hours by air, the problems we are struggling with are being solved." He ended his presentation with a series of recommendations for changes in the policies of the Minnesota ARC regarding institutions.

In the autumn of 1966, the Minnesota ARC established an extensive policy platform for legislative changes, aimed at broadening services in the community and modifying institutions to serve smaller numbers. I was invited to visit for a few weeks to help "bridge the gap between Europe's advanced methods of care and our outdated practices," according to their newsletter. At the same time, I got to see for the first time the huge, desolate wards of American institutions. The visit, in March 1967, was an intense experience: walks through institutions, views of workshops and community programs, and talks to various groups, from early breakfast meetings, luncheon addresses, and radio and TV interviews, to evening lectures. On the very last days I had 13 "performances" a day, with my form and confidence getting better and better. I learned a little about the meaning of "running for office," and I met some people who had. A magazine reported: "He talked for an hour with governor Harold LeVander, had lunch with Hennepin county legislators, and spoke at a House subcommittee meeting at the invitation of the chairman."

This first tour brought with it reciprocal shocks: American audiences were shocked by my slides from Swedish programs, and I was shocked by what I saw in the institutions, which opened my eyes and camera. In my presentations I used slides, sometimes as many as 80, forming a narrative about the normal rhythms of the day, week, year, and life cycle in Swedish institutions and communities. Without them, I might not have been believed. These slides provided my words with the impact of realism. Several times I encountered the reaction that Jerry had once displayed, with people in the audience wiping their eyes. I was a decent photographer, capturing scenes that fit the movie in my mind and illustrated my narrative and analysis. My slides were parts of my memory. I never took a picture of persons that showed something that they did not want me to photograph. On the other hand, institutions are public places, with no privacy. If the results were shocking, it was not of the residents' doing. So I sometimes took pictures despite the protests of persons in authority.

The stages offered by the large U.S. institutions felt too large for my simple little camera. The ARC newsletter writes about my visit to Faribault State Hospital:

where he saw large wards with as many as 104 patients with "little staff and no program." He used words such as "horrible," "inhuman" and "impersonal" to describe the situations he saw, "things I am deeply shocked by, that I did not think existed. ..." "That's degrading human beings in a way I have never seen before. ..." "The horror of the situation came to me afterwards, when I realized that I was not able to remember any single person, only abstract beings moving around; as you say, it is a dehumanizing effect. ..." "It is an utterly costly system, a mismanagement of human resources. Patients who aren't receiving needed services now are doomed to be severe-care cases for the rest of their lives—and in the long run the cost will be much greater. ..." [H]e expressed many of these thoughts to Minnesota Governor Harold LeVander in a private meeting on March 15 in the Governor's office. (Minnesota ARC, 1967a)

Under the headline "Retarded Need Chance for Normal Life," the newsletter (Minnesota ARC, 1967b) presented quotes such as these:

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“Mentally retarded people should be able to attain an existence as close to the normal as possible...”

“Normal means the normal rhythms of life, whether it be home life, institutional life or educational life. It means normal standards of housing, the same kinds of schools, the same kinds of hospitals, the same kind of medical care as are provided for the rest of us...” “It means learning how to develop and grow into adulthood, to have responsibility, to play a role. Such a sense of role-playing should be given to the mentally retarded person whether he is in an institution or living at home. It means the normalcy of working, or travelling or having free time—we aim to have integration of the mentally retarded in our social living...” “It means abandoning the concepts that the retarded are always children and planning help for them to live through a complete life cycle.”

So there it was, in a nutshell, in black and white, most likely in print for the first time.

Nirje said that the Swedish Association also is working for the Normalization of the parents’ situations, of the attitudes of authorities and the general public. . . . [He] told how the principle of normalcy had been applied in the development of Sweden’s institutions: in the 1930s, we were planning for units to serve 40 residents, in the 1940s it was down to 30 per unit, in the 1950s to 20, and now we are building small units for six to eight persons, the number of people one might find living together in normal home conditions... . [He] showed slides of some of the newer institutions, where patients sleep in single or double bedrooms in which they have their personal belongings. Dining and all living activities are in small groups.

Such were the themes and statements in the presentations, including some in Iowa and Wisconsin. The most memorable for me took place in Lincoln, Nebraska, on March 11, 1967, where I was exposed as a banquet speaker without appetite to a very large audience with hungry eyes. If memory serves me correctly, it was in this presentation that, for the first time, I put in some fresh slides from Minnesota institutions as telling contrasts to further illustrate my analysis. Anyhow, I got my first standing ovation. And in the audience was Wolf Wolfensberger. Afterward, we were introduced to each other but had no opportunity to talk. The occasion was the NARC North Central Region meeting and the scene after the speech and the banquet was very lively.

During my stay in Minnesota, I was introduced to U.S. Vice-President Hubert Humphrey, who invited me to his home in Washington, DC, where I showed my slide presentation to Muriel Humphrey and some guests. She was a very knowledgeable and interested “grandparent.”

My stay in the USA was extended, as I had been asked to visit the President’s Panel, see a new institution in New Jersey, and give a presentation organized by Elisabeth Boggs. My visit to the Special Olympics office, where I advised them also to take up wheelchair events, resulted in an invitation by Senator Edward Kennedy to go to Boston to give a banquet speech at the Harvard Club. There, to give me a bit of assurance, I asked that the lectern be placed in front of the plaque honoring John Quincy Adams, one of my favorite American statesmen. Before the lecture, I had been invited to the office of Governor Volpe for a conversation, and among the banquet guests was Elliott Richardson. Both of these men came to play significant roles in the next U.S. administration, which took over 10 days after the publication of Changing Patterns.

During these intense weeks in the US, I had seen a number of institutions that were 10 times as large as the one I had shown Jerry Walsh, which was one of the five largest in Sweden. I had been in vast, foul-smelling dormitories for over 100 persons, and in dayrooms that had hardly any furniture, with no activities or functions for the half-naked inhabitants, who were anonymous. The inactivity of the residents was made worse through a medicated passivity that assisted the sparse staffing. At the same time, I had had the opportunity to concentrate on and develop my own thinking, analysis, and expressions through my talks, discussions, and lectures. Step by step, as it were, I had conquered a feeling of doubt concerning the validity of my point of view and became confident that it could serve as a tool for constructive analysis and criticism. The services enabling normal conditions of life in the community had to be significantly strengthened to allow for the abolition of these monstrous institutional abominations—and not only in the US.

I finally returned to Sweden in April 1967, where it was work as usual but with a new ingredient: preparing for the Stockholm Symposium on the Legal Aspects of Mental Retardation, held for the International League of Parent Associations. There were also preparations for informing the intellectually disabled about the
change from driving on the left side of the road to the right side. After the Stockholm symposium, described earlier, we all met in Montpellier, France, for the 2nd Congress of the International Association for the Scientific Study of Mental Deficiency.

At the congress, one seminar was on “The Adolescent Retardate,” chaired by psychologist Emanuel Chigier, of Israel, a specialist in group dynamics. Among the speakers were S. Masovic, from Yugoslavia, my old friend Elliot Avedon, from the US, and I. My subject was “Integrational Know-How: Swedish Programs in Social Training” (Nirje, 1967), which described our efforts to provide adult education programs, activities to increase social competence, and club structures, as well as provided examples of demands made by young adults themselves. As background, I commented on some facts from a study conducted by Lennart Wessman that looked at the need for vocational education:

A few years ago an investigation was made in Sweden of the conditions of life for the about 1,500 young men and women of IQ 50-70 who now are 25-30 years old and who left Special School during five years in the 1950s. More than 50% were jobless and had to live on pensions, 50% were found to be shy, reticent, insecure, withdrawn, without friends. Only 10% took part in regular leisure time activities. These are not conditions of life that are close to the normal. The loneliness and isolation of the adolescent retarded are crushing conditions of life—far harder than those of the normal youngsters. And they lack the self-defence, the force to rebel. In the opening of the paper I made these statements:

In Scandinavia we usually say that the aim is to give the mentally retarded an existence as close to the normal as possible—in their daily life and in the regular community. How does this principle apply to adolescents? For instance, there ought to be a normal daily rhythm—not having to go to bed earlier because you are retarded; a normal rhythm of the year, including summer vacations and not having to go to camps for children when you are 16 or 18, but instead a summer course as other youngsters do; normal routines of life: a home, a place to work, leisure time activities; the normal development of life: growing from childhood through adolescence into adulthood; and being respected as an adult.” (Nirje, 1967)

I believe that this was the first time the Normalization principle was mentioned in such an international context. With only 30 people or so in the audience, the impact was discreet. Anyhow, partly hiding behind the authoritative “we” that expressed an attitude shared with some professional friends, I presented a basic summary of the main facets of the principle, still without having completely understood its deeper meaning and significance.

12 THE WRITING

The Stockholm symposium and the Montpellier presentation led to an invitation to go to Israel to advise on legislation, to assist in preparing the upcoming Congress in Jerusalem of the International League of Parent Associations, and to study the group-dynamics approach of Manny Chigier. The Israeli parent association, AKIM, published the Montpellier presentations. I went to Israel in February 1968. The country was still quietly grateful for its youth. After all, 1968 was to be the year of youth but also of violence: the demonstrations in Paris, Chicago, and Prague, and the Martin Luther King and Robert Kennedy assassinations.

Before this travel, I had received a letter with another special request. It came a few days before Christmas 1967, written on behalf of “Dr. Robert Kugel, Chairman of the President’s Committee on Mental Retardation,” by his assistant, “Wolf Wolfensberger, PhD, Mental Retardation Research Scientist.” The letter told about “a project aimed at reviewing residential care programs for the retarded in the US, and in speeding along innovation in this area.” The planned publication had as its theme “Toward Innovative Action on Residential Care.” Seven sections were foreseen, and I was asked to write for the one called “As Others See Us”: “On your visit to Nebraska, we were impressed with your forthright and eloquent evaluation of US residential centers. We are hoping that you would write as you spoke, giving Americans the chance to have their residential services evaluated by someone coming from a nation with more advanced social services. We suggest that you mince no words, but be direct and forceful.”

The letter went on to state that “The President’s Committee is under intense time pressure.” The deadline was February 29, 1968,
and the paper should be written so as to be intelligible and appealing to professionals in other areas, as well as to intelligent and educated laymen. . . . Indeed, it might not be a bad idea to pretend that you are trying to inform a busy, intelligent, uninformed but sincere, unbiased and sympathetic legislator. (Wolfensberger, personal communication, 1967)

Thus, my paper was to be short, simple, and soon, with the subject being my views on large U.S. institutions.

The letter was certainly more of a shock than a kind of Christmas present. I answered on January 17 with a hesitant "yes," because

I have no definite notes on my talks in the US. I always speak without a script. However, my impressions were and still are vivid, and I think I can give a fair description of and the motivations for them. . . . I hope you are aware that I only saw very few residential institutions during my stay, and the main experience was Faribault. I then very quickly visited the Central Colony in Madison, Wisconsin, and afterwards spent a day at Woodbridge, New Jersey. . . . But my reactions are not mainly to a geographical place or house, but to specific situations and standards within an institution which, when described, will stand for a recognizable type. . . . The main line in my paper will be a description of what we mean here by Normalization, which forms the base for my evaluation of the US facilities. (Nirje, personal communication, January 17, 1968)

I asked that a copy of Christmas in Purgatory (Blatt and Kaplan, 1967) be sent by airmail, as the letter of invitation had come to me by boat and had taken three weeks.

The point of interest here is that I was not asked to write on the principle of Normalization, an unknown entity. Instead, I was to write about institutions—and almost a year had gone by since I had seen any, and I had no notes. Time was of the essence, and I had my hands full with other commitments and duties: the visit to Israel; the FUB magazine had started; the courses in social training; the biannual FUB congress in May; the need for more staff; and, not least, the new law that was coming into effect, with all the information required by and for the local associations. The request from the U.S. President's Committee was not very popular with the FUB executive board. Jerry Walsh, who was now at NARC headquarters in New York, came to my rescue. For my trip to the US, he arranged for me to give a few talks and to see some institutions—for I felt I had to see more and have fresh impressions to write on—and also to discuss the situation in general. The President's Committee offered the services of their office in Washington for the final work. I was allowed to take a few weeks of vacation to get there.

So after the FUB congress at the end of May 1968, a few days after the death of my closest friend and the murder of Robert Kennedy, I flew to the US. I find that the plane is always a good place for relief and concentration, and I remember making notes on the eight facets of the principle and finding their proper order. I must have made other notes as well—or brought them with me—because, while I was writing the present chapter, Wolf Wolfensberger sent me a copy of a memo I signed on June 12, 1968, at the NARC offices, a few days after my arrival in New York. The memo consisted of six concentrated pages, on issues that I must have been grappling with from the time of the December request. I had completely forgotten about this memo, but I certainly recognize my own writing and ideas. The memo had a very heavy heading: "Outline for a plan to attack inhuman conditions in the United States' institutions for the mentally retarded." The plan contained strategy and tactics, targets, and logistical needs. Because it has never been published, I have included it at the end of the present chapter as an appendix. Why did I not include parts of this memo in the paper I subsequently wrote for the President's Committee? I probably looked upon the memo as confidential recommendations and advice to NARC. I would continue to deal, in papers to come in the following years, with the concerns expressed in this outline regarding what came to be called deinstitutionalization. The points expressed concerned the U.S. scene of the time, but the stand and approach were the ones I later brought with me to Canada, and to Ontario institutions, for further development.

With the load of that memo off my chest, I could go on to visit institutions. On June 13, I saw my old professor Norman Holmes Pearson at Yale University. That day, he autographed a book for me. At Yale, I met up with John Belmont who took me to visit Southbury. And then my friend Frank Kelly showed me a large institution south of Boston. There, I remember quite vividly the smells in one building that forced me to go
outside and throw up—my nose had always served me well on inspections. Frank comforted me, saying: "Bobby Kennedy puked here too; we will put up a plaque!" After a speech I gave to a large regional conference in New Hampshire, I returned to New York to visit Letchworth, a large institution on the west side of the Hudson River, where, in the 1930s, as a fairly new arrival to the US, Gunnar Dybwad had worked. I was surprised to find that at Letchworth they had different burial grounds for men and women. These were on opposite ends of the small (institutional) city where 5,000 people (not including staff) lived in the drab barracks of the old institution.

I returned to Hyde Park, for a return visit with Jerry and his family, to gather my strength. Then, the moment of truth "soon" arrived when I reached Washington, DC. Installed at the old Willard Hotel, I spent three days "locked in" at the Department of Health, Education and Welfare (HEW). The procedure was simple: With the help of my notes, I dictated to three secretaries, who took turns. I stopped dictating to the second when the first came back with her part for corrections, and so it went. First came the impressions of the institutions, with comments, which took up four pages. Then came the rationale for the criticism, the Normalization principle, which took up eight pages. To the paper was added a seven-page translation of an article I had written on the new Swedish legislation.

When Changing Patterns was published, the four pages on institutions were placed in a section with Burton Blatt’s Purgatory. My contribution was late, and certainly short. The “Normalization Principle” part of my paper—with the appendix on the law—was placed in the section “Toward New Service Models.”

I had been asked to write about U.S. institutions, not about what I called the Normalization principle. But I needed to state the principle as a basis for the criticism of the conditions of life for persons with mental retardation in such environments. I should add, however, that the principle described a view of the general situation of disabled people in the community.

But of these editorial considerations and decisions I knew nothing at the time. At the end of the three days of intense concentration, I left HEW. In the beautiful midsummer evening, I walked across the Mall, with a thorough feeling of relief and happiness. I can never see that magnificent Mall without remembering that crossing.

13 AFTERWARD

Thus, it all came together: the involvement in literature and academic education; the orientation toward human rights and international cooperation; a humanistic and multicultural approach; the group-dynamics experiences and the voices of refugees; young adults with cerebral palsy and intellectual or other disabilities; the legislative concerns and the social interests of parents and the disabled; the drive to find a shared language that would provide a common ground for the many specialties and special interests involved; and the international developments and stimulation. All of these factors and experiences had, at different times and in different ways, contributed to and shaped the forming of the Normalization principle.

Opportunity and need also conspired. Without the problems that I and other visitors had seen in American institutions, the invitation of the President’s Committee, and the resolute actions of Jerry Walsh, the paper on the Normalization principle might never have been written. Moreover, the invitation and request had asked for my impressions of large institutions, not for the Normalization principle! To offer such a critique required, I felt, a coherent and explicit point of view. This first version had given me a platform, as well as binoculars and a magnifying glass, with which to view and expand on further experiences. But I knew none of this at the time. Then, I was mostly happy the ordeal was over. There certainly were tasks and troubles enough to handle in my job.

Later in 1968, I learned of the editors’ decision to divide the paper into two parts and that they were pleased. At the end of the year, I think I was also told that Gunnar Dybwad had highly appreciated my contribution. The positive reception of my work was indeed confirmed when Grunewald and I each received 10 complimentary contributors’ copies. We gave most of them to colleagues. In this way, the principle became known in Sweden, and later in 1969 a translation was published both in the FUB magazine and in one of the two professional journals. The FUB, however, was not impressed. Before its publication, I was permitted to read it to the board, but no discussions were allowed. I think the general attitude was that the paper was a nice, commonsensical presentation by a well-meaning amateur who should
not travel abroad so much. Board members had not authorized these views, which were probably controversial. But people stopped saying that the views on American institutions were exaggerated. Swedish institutions, on the other hand, were thought to be so good that one did not need to speak about them. So members did not think there was a need for a special principle, other than one based on common sense.

Such issues were, at that moment, only minor concerns. There was much to be done. The new legislation was starting to be implemented in all 23 counties. Many programs—over 50—run by the local associations could at last be handed over to the responsible county financing authority. And the youth clubs were growing like mushrooms. Soon, there were over 40 of them.

Since 1962, I had been a member of the advisory committee for sports for the disabled, including the intellectually disabled. Changes were needed and because I took the initiative, I was given the responsibility for founding the Swedish Handicap Sports Association (SHIP). This took place in May 1969. This new organization meant that the sections devoted to sports of the various handicap organizations became independent sports clubs. These were grouped into districts, and the whole organization immediately became a member of the Swedish Sports Federation. Thus, our committees for the various sports practiced by handicapped athletes, whether paraplegic, amputee, deaf, cerebral palsied, or intellectually disabled, had direct relations with the equivalent Swedish Sports Associations. I had written the constitution and was elected vice-chairman. As I spoke more languages and had more international experience than other board members, I became our first international representative, joined later by other Swedish colleagues.

Between 1971 and 1995, I was elected to a number of positions in international sports federations for disabled persons. In 1986, I could at last finalize the preparations for the founding of the International Association for Sports for the Mentally Handicapped (INAS-FMH). As our clubs tended to be locally based or to become parts of regular sports clubs, sporting activities became one area where intellectually disabled athletes could share and take part in normal adult activities and social relations. INAS-FMH has now become a founding member of the International Para-Olympic Committee (IPC), and since 1992 intellectually disabled athletes, together with other disabled athletes, have been able to compete in summer and winter games and in world championships. The Swedish organizational model was followed by other countries, but only a few included intellectually disabled athletes. In Sweden, they were present from the beginning. Not all members on the FUB board appreciated this, and I was told that there were certainly more important issues to deal with than sports. Until 1995, when I resigned as vice-president of INAS-FMH, the international development of sports for handicapped athletes was an important area of endeavor for me. This involvement in sports has given me great satisfaction.

Back to 1969. While all of this was going on, Wolf Wolfensberger arrived in Stockholm by train with Bank-Mikkelsen from Copenhagen. We had only met casually, but now he was in my home for a week and the next week he stayed with Karl Grunewald. Wolf has told me that when he first heard me at the banquet in Lincoln, Nebraska, he thought the ideas rather good but nothing remarkable. When he read my paper as co-editor of Changing Patterns, he found it quite good and interesting. Then Gunnar Dybwad advised him to go to Scandinavia to see for himself how the situation of the intellectually disabled looked in a different cultural environment.

Right from the train station, we walked a few blocks and visited an apartment used by some of our clubs for meetings and activities. While I discussed some business in a meeting with some members, Wolf was introduced as an American visitor and left to form his own impressions. I remember vividly Wolf standing in a corner watching the dancing that had started—a birthday was being celebrated—and then he hesitantly asked me: “That girl, she asked me for a dance, and we did. Is she...?” She spoke some English, and so he did not quite know whether she was a typical Swedish girl who happened to speak English or really an intellectually disabled girl who had learned some English. I assured him she really was the latter.

On the way home, I explained the purpose, functioning, and activities of the club. Half of the members were disabled, and all the positions on the elected board were held by an equal number of disabled and nondisabled persons. The nondisabled were trained to let the disabled make the decisions about the activities. Later, we talked a great deal about
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his many visits to programs and facilities and with key persons in and around Stockholm. I remember a particular discussion when Wolf was upset by all the nice, new, modern furniture he had seen in a renovated institution. I had to explain that quality was more economical in the long run and that it was quite normal to buy regular furniture from regular firms, as people normally do. Moreover, the counties were likely to get better prices because of the quantities we purchased. Old and recycled furniture of a decent standard would turn out to be far more expensive. "Scandinavian design" did not imply luxury in Sweden. I do not know if it was this experience that led him to his "conservatism corollary" (Wolfensberger, 1972). He spent the following week with Karl Grunewald, learning about the Swedish organization of services and the controls over quality that were used.

In 1969, I wrote a paper entitled “Toward Independence” (Nirje, 1971) for the 11th World Congress of the International Society for Rehabilitation of the Disabled, in Dublin. There, I presented my own interpretation of “mental retardation”—the individual cognitive impairment, the learning deficiencies, and the awareness of the handicap—and applied it to the programs and living conditions on three levels of functioning. I had discussed my model for the definition of intellectual disability with Gunnar Kylen, who encouraged me to write about it. He had been the psychology expert in Grunewald’s office and, on my initiative, he was now the research director of the ALA Foundation, which had been started by FUB to stimulate sheltered workshop developments. The programs for the three different levels were a simplified version of the views I had expressed in my recommendations for U.S. institutions. The paper, which started and ended with examples, explained that the aims of social training, adult education programs, and club and conference activities were to support adults who were striving for independence. This theme was later to be developed in greater detail in my paper “The Right to Self-Determination” (Nirje, 1972a).

This paper was written under very special circumstances. At the same time as the Dublin congress, a symposium on institutions was being held in Frankfurt, Germany, organized by the International League. I had been invited to speak at the symposium but it was decided that I should not go to Frankfurt. Instead, a parent would attend, and I could go to Dublin. At the last minute, the parent chosen got cold feet, so I was ordered to go to Frankfurt and to cancel Dublin. This sudden decision complicated things for me, for, as I usually did, I had made some notes and mulled over my presentation in my mind. Right after I was told of the decision, I biked to my office, angry and upset, and started at 5:00 p.m. to write. At 5:00 a.m. the next morning, I left the manuscript at a hotel near the bus for the airport, where a person headed for the Dublin congress picked it up. She was allowed to read it in my stead. I was happy with the result, but the circumstances of writing were certainly not those one would wish for.

I flew to Frankfurt, for a rather miserable symposium experience. The first session dealt with the Normalization principle. In a surprise move, I was appointed secretary of the session, but after a while I was told that secretaries were not allowed to take part in the discussions. One of the German participants, who was highly agitated, burst out that Nirje’s principle meant that the most disabled should live at the bottom of society, “mit die Dieben und Huren!”—with the thieves and whores! At this point, Bank-Mikkelsen had had enough and, in no uncertain terms, demanded that I should be allowed to take part in the discussions about my own ideas! Alas, the symposium did not measure up to Changing Patterns.

14 CRISIS

The events around the two international conferences were additional indicators that the mood within FUB was changing. There was no longer the same enthusiasm regarding small, local programs, because these had now been handed over to the proper authorities. Instead, there were all these new programs for young people: clubs, adult education organizations, and sports clubs, and the need to find voluntary helpers for all of these endeavors. The new law also brought about changes in residential programs, and not everybody was happy with these. They did not know if the new system would work and guarantee quality care. Could the new types of group homes really be as good as the rather recently built, nice institutions? Voices against
these developments were now heard from new board members. Some thought that international relations were now of less importance because they felt that we had less to learn and were spending more and more time assisting with developments in other countries. As we had grown in numbers and responsibilities, I had recommended changes in the operation of our office. Those changes were desired by a majority of the staff but were not popular with a majority of the board.

My job required a lot of travel, to local or county associations or to courses and conferences around the country. On my return, there were often new problems and irritations in the office. All in all, the atmosphere had changed, and too often the mood was negative. Moreover, I was the ombudsman, and I believed that the association was a spokesperson for all intellectually disabled persons, whether their parents were members or not and irrespective of where they lived, be it in institutions or in the community. We should act and speak on behalf of those who were blind, had cerebral palsy, were deaf, were multidosable or mildly disabled. There were other groups defending the institutions who, in advancing economic reasons that they hoped slow-moving county boards would support, wanted to decrease the pressure for deinstitutionalization. Not everyone appreciated the new attention given to young disabled adults who, more and more frequently, were being interviewed in the newspapers and receiving more space and attention than parents. And, not least, FUB was a parent association; it was the parents who should be heard, and I was not a parent.

Thus, at the 1970 biannual general assembly, in Malmö, the more negative voices elected more representatives to the board and the executive committee. The chairman was made executive director as well, in effect replacing me. Earlier, two staff members had moved to a lawyer’s office to concentrate on legal matters, and the chairman took on the responsibility of coordinating what were now two branches. While this was going on, a three-day conference for 50 intellectually disabled young people—one man and one woman for each of the 24 counties, and two Danish guests—worked out the statements that I eventually presented at the end of the chapter “The Right to Self-Determination” (Nirje, 1972a). I was unable to attend this conference, as I was tied up with the general assembly. The youth conference attracted far more newspaper coverage than our routine general assembly.

A few weeks later, the board held a meeting, mainly to discuss a response to the youth conference. It quickly developed into a stormy meeting, where the apparently well-prepared negative voices expressed their dislike and distrust of the program and the proceedings. They did not trust the results, stating that the disabled could not have come to these conclusions by themselves, but that they must have been instructed and directed. They concluded that such programs had to be controlled by the parents—of course, none of the persons speaking were parents of the conference participants. At the end, the two young women who had been in charge of organizing this perfectly arranged conference rushed out of the meeting in tears.

This new backlash was hurting. Afterward, I heard I was a danger to the intellectually disabled: “Nirje teaches them that they can think!” Others repeated that I was not a parent and too radical, “even worse than Karl Grunewald!” Some days later, by misfortune—or good fortune—I happened to overhear the chairman, from the telephone in my office, inform someone that “Nirje’s Normalization principle is his private idea and not the line of FUB” and that the youth activities should be controlled by parents. The chairman added that he was not worried that I might leave, “now he knows nothing else.” Shocked, I took a long walk and, upon my return, asked for a luncheon appointment with the chairman. When all I got were vague and evasive answers, not in keeping with what I had overheard, I made up my mind. There was no basis for confidence left.

Over the weekend before midsummer in 1970, I cleared out my desk and wrote a letter of resignation to the board members, quoting from the views expressed by the chairman in our conversation but not mentioning the words I had overheard. I then left the office for good. I felt it would only be conflictual if I stayed. My role had become impossible and compromised. It was a traumatic experience, but necessary. Had I stayed, I might have had to contribute to harming disabled persons. Now the association had to face issues without my advice. Now they were free, but so was I. And without a job.
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15 A NEW START

It would be a year and a week before I would start a new job. To begin with, I had a lot of unused vacation time, which was needed. As luck would have it, the World Games for the disabled were scheduled to be held in St. Etienne, France, during the second week of my newfound free time, and I had been appointed “chef de mission.” Because we were now members of the Swedish Sports Federation, we were allowed, for the first time, to wear the national colors. About 50 of us, paraplegic, amputee, and blind athletes and leaders, were flown down on an air force Hercules. The team was quite successful, which boded well for the future. But we also became aware of all the problems involved with different national approaches to the classification and interpretation of impairments. Without a proper and adhered-to classification system, the basic sporting goal of competition with fair play and on equal conditions is, at best, very difficult. There was much work to be done during the coming years. But we flew back with 13 gold medals and a strong team spirit, which continued through the years.

In August 1970, the 3rd Congress of the International Association for the Scientific Study of Mental Deficiency (IASSMD) was held in Warsaw, Poland, and Karl Grunewald and I drove down together. Poland felt like an occupied country, which was quite appropriate, given my mood. Gunnar Dybwad had advised me to speak to a Dr. Zarfas from Canada, who was interested in hiring people, but I felt too tired and dejected to try to find him. I spent most of the time with the architecture group around Bank-Mikkelsen and Arnold Gangnes, from Seattle. In April, I had been invited to speak at the annual meeting of the British Parents Association and, on the ferry back to Sweden, Herbert Gunzburg, editor of the British Journal of Mental Subnormality, engaged me in a long conversation that ended with my promising to write a paper on the Normalization principle and how it applied to profoundly and severely disabled persons.

In order to do a good job on this paper, I went to the special state hospital, Vipeholm, in Lund, where I worked as a ward attendant’s assistant with the most disabled and self-injuring residents. Here I met Ingrid Liljeroth, who led a small ADL-training program for persons who had been brought out from the wards and who were living in single rooms, with varied schedules and one-to-one support relationships. This pioneering program opened the way for more positive services in the field. It would also help me explain, later on, how things could be done to assist profoundly disabled persons to have a normal day, a normal week, and a normal year. I was thus able to write my paper, which included part of “Toward Independence.” It was called “The Normalization Principle: Implications and Comments” (Nirje, 1970). Thus, the principle became known in the British Commonwealth, and here and there around the world.

Jerry Walsh knew of my predicament and thought that I could be put to some use. He made an agreement with his Wisconsin colleagues, Merlen Kurfth and Harvey Stevens, the state commissioner for mental retardation, that Wisconsin could have me for three weeks and Minnesota for one, thus reversing the 1967 arrangement. So, in November 1970, I happily left for the States, with new photos added to my presentation, such that the photos could now be chosen to fit the interests of the various audiences. I also had special presentations for social training, leisure-time activities, parliamentary-technique courses, and conferences for young adults, which could include demonstrations of my “attitude-changing machine.” The theme of these different presentations was the importance of the right to self-determination for persons with intellectual disabilities.

In Wisconsin, I spent a few days at each of the three large “colonies”–institutions for more than a thousand persons–visiting wards and programs and lecturing to group after group of staff and administrators. I also visited all 10 Wisconsin regions, to talk to the local parent associations. Then, by automobile, I did a quick tour of Indiana, and then went on to Seattle, Washington, and Arnold Gangnes’, for a New Year’s celebration. Some parents from Vancouver flew in to one of my lectures and insisted that I come with them, which I did. I very much liked my first taste of Canada.

Then it was on to Nebraska and ENCOR, where I found a worn and tired Wolf Wolfensberger. I returned to Wisconsin and then to Pennsylvanina, with one request after another coming in through Jerry Walsh. I now enjoyed my lecturing. I always spoke without a manuscript from a list of points, gradually polishing formulations and angles. I especially liked the question-and-answer periods, in which concerns and
problems were expressed. These experiences and lectures became the context and build-up for papers later written in Canada.

I had yet to meet Allan Roeher, but I got an invitation to speak at his National Institute for Mental Retardation (now the G. Allan Roeher Institute) in Toronto and to meet Don Zarfas. I was later given to understand that it was Rosemary Dybwad who had insisted that I go there. After the lectures at the institute, I was invited to stay with Don Zarfas and visit some institutions, to talk about these and to talk with the staff. After a few days, on the way from the showplace institutions—the Children’s Psychiatric Research Institute (CPRI) in London, Ontario, and Palmerstone—to the old large institution in Orilla—I was asked if I would consider a position on Don Zarfas’s staff. I liked what I had seen so far. I asked to see the worst and the best, which I did. I also spent a few days with his two assistants, one responsible for staff development and the other for community relations. My task would be to coordinate training and program development for Ontario institutions, where about 11,000 persons lived, with the two largest housing over 2,500 residents each. My participation was also wanted in preparing the changes needed so that people could move into the community and in giving lectures in the staff-development programs. I had seen much worse scenes in U.S. institutions, and I liked the positive atmosphere and the desire for change. At the end of the week, I accepted. I phoned home and said I had a job in Canada.

On the way home, I was invited to give a few lectures at Syracuse University and at last had the pleasure of meeting Burton Blatt. It was March 1971, and I had been away for almost four months. On July 1, I started work at the Mental Retardation Services Branch in the Mental Health Division of the Ministry of Health of the Government of Ontario. I, who had tried in many ways to demonstrate how wrong institutions were, was now partly responsible for them! But there were people in them who badly needed training programs, evacuation plans, and preparatory planning for obtaining new kinds of services in the community. Later, I would be shocked by the cold attitude some people took toward the persons left in the institutions, in advocating that all the money go to programs run by nongovernmental agencies in the community.

So, I left Sweden and cannot be blamed for the developments that took place there. In what ways my Normalization principle had anything to do with these is not for me to say, for I do not know. What might I have accomplished had I stayed on as ombudsman and gone on as before? I know for sure that there were four things that I would have attempted to do: (a) provide training, to strengthen the capacity of the county associations to tackle the planning required by the new law; (b) promote coordination between pedagogical developments in adult education in the Folk High Schools with those taking place in adult education organizations, foster the development of easy reading materials, and stimulate pedagogical research at the ALA Foundation, thereby unifying efforts to strengthen the social life opportunities of the adult disabled; (c) clarify that the Normalization principle covered all disabled persons and their right to self-determination and expressed a perspective on rehabilitation; and (d) develop cooperation between the Handicap Sports Association, other relevant sport associations, and handicap organizations, in line with principles that I had included in the constitution of the association.

Be that as it may, I left Sweden—for good, I thought—and the only link left was the Handicap Sports Association. They had nominated me for a position on the board of the International Sports Organization for the Disabled (ISOD). Throughout my years in Canada, they took on the extra cost for my attendance at meetings two or three times a year, mostly in Stoke-Mandeville, England. During the following decade, considerable changes were to take place, most of which were positive, and it was a pleasure to be an instrumental part in the struggles to come. There, at least, I was not alone.

16 IN CANADA

The same week I started work at the Ontario Ministry of Health, Walter B. Williston, a prominent lawyer and a dynamo, began a six-week investigation that resulted in his report Present Arrangements for the Care and Supervision of Mentally Retarded Persons in Ontario (Williston, 1971). The previous spring, two young men from a large institution in Smiths Falls,
Ontario, housing 3,000 persons, had escaped from the farms where they had been placed. One had hung himself and the other, who had been lost, was found with severe frostbite. The minister had given Williston the task of carrying out a complete legal analysis of the whole service system and of making recommendations. Williston and his office worked with extraordinary speed and thoroughness. Don Zarfas, Connie Hawley (my colleague responsible for community relations), and I worked closely with Williston. With him, I visited institutions and explained my views of them. I made him familiar with some important new literature, including Changing Patterns, the work of Edgerton, Tizard, and Blatt, the symposium reports of the International League, and the new Swedish legislation.

The Williston (1971) report catalogued institutional failings and demonstrated the lack of coordination among existing community services. It also showed the lack of coherence and efficiency among the responsibilities of the many ministries involved in financing and overseeing the numerous pieces of legislation involved. The report brought about important changes that renewed the Ontario approach. It was followed by two additional government ministry reports, with recommendations for step-by-step changes that led to the transfer of all mental retardation services to the Ministry of Community and Social Services.

These were years filled with rapid changes, new initiatives, and new resources. In the autumn of 1974, under David McCoy, some of us, including John Webster, Burt Perrin, and I, worked on a plan to establish a detailed compendium of social services. It listed types of accommodation, occupational opportunities, family-support options, leisure-time activities, day-care options, and "adult protective service workers" who were each to assist no more than 40 disabled persons in the community. This compendium eventually became known as The Blue Book, and in March 1975, it was accepted by the legislature of Ontario.

In September 1971, a few months into my new job, I had the pleasure of personally welcoming Elliot Avedon to Waterloo, Ontario, and Wolf Wolfensberger to Toronto. Wolf told me that he was writing and editing a book and asked me to write about my ideas on social training and adult education. This became a chapter, "The Right to Self-Determination" (Nirje, 1972a), in Wolfensberger's (1972) book on Normalization. It took some time before I started to realize that my concept—which had been written with many cultures in mind and had been published in an official U.S. publication, in plain English—had been "Americanized" and slightly twisted by Wolf. Over the years, this became somewhat embarrassing, especially when some of his students, who had been unaware that happened to be in the audience, objected to my correcting their glaring mistakes and misunderstandings!

At the 1972 Montreal Congress of the International League, I presented some of the things I had been stressing in my lectures in the USA and Canada. My presentation was entitled "Application of the Normalization Principle: Comments on Functional Planning and Integration" (Nirje, 1972b). "A funny thing happened," as the saying goes, at the Montreal congress. The rather large room for the session where I presented my paper was overflowing, with people standing along the walls and sitting on the floor. Right in front of me, in the very first row on the floor, sat Niels Erik Bank-Mikkelsen. After the presentation, I saw a beanstalk of a man rise from the floor in the back and, with giant steps, climb over the people in the aisle, including a surprised Niels Erik. A whisper went through the room, a whisper I could not make out. The man put his elbows on the edges of the lectern, his head in his hands, his eyes staring straight into mine: "But, Dr. Nirje, if the world is not normal, what then?" I swallowed and said something like, "wherever we are, a day starts, a week goes by, the years pass," and then, grabbing for Hemingway, I added, "'and the sun also rises'!" "Oh," he said, "now I see: You are a poet too!" Thus I met for the first time the remarkable Jean Vanier. It was indeed a pleasure to talk with him and assist him on a later occasion, even though we came from different directions.

At the Ministry of Health, and later at the Ministry of Community and Social Services, I had my papers distributed to colleagues, personnel in training, institutional staff, and staff in district offices. In 1976, I was asked to contribute to the bicentennial issue of a new version of Changing Patterns for the President's Committee on Mental Retardation. They wanted my paper on the Normalization principle brought up to
date, so I included parts from the paper published in the *British Journal of Mental Subnormality* (Nirje, 1970), from “Toward Independence” (Nirje, 1971), and from the Montreal presentation (1972b), with some additions, updates, and clarifications. This paper (Nirje, 1976), with some revisions, including a new appendix entitled “On Integration,” was reprinted (Nirje, 1980) in Flynn and Nitsch’s (1980) book *Normalization, Social Integration and Community Services*. In a way, this closed a circle. The additions to the original papers were done. What came later were perspectives on the principle from various angles and its relation to basic ideas on ethics.

It was stimulating to work with the new people and the new opportunities in the districts around the large province of Ontario. But there were frustrations, as the “higher ups” seemed to have cold feet in the face of the dynamic developments and program demands in the districts, where people did not hesitate to go to the parliamentary representatives to get what they wanted, which was not, however, always related to the proper priorities.

In 1978, for personal reasons, I returned to Sweden. It was possibly a mistake, as Sweden had changed in ways that I did not at first appreciate. I became a Care director in Uppsala county and found myself tied to an already existing five-year plan that I did not feel met the requirements of the law. In 1983, a heart operation forced me to leave this position which, in a sense, took care of these problems. In 1985, I became associated, on a part-time basis, with the development of the Uppsala University Centre for Handicap Research. I returned to Toronto for the 1982 International Association for the Scientific Study of Mental Deficiency (IASSMD) Congress where, with the Uppsala group, I presented “The Basis and Logic of the Normalization Principle” (Nirje, 1985). This paper describes the relationship of the principle to scientific theories in the fields of ethics and anthropology. It also presents my basic criticism of what I have called “the Wolfensberger fallacy.” With Burt Perrin, I coauthored the paper “Setting the Record Straight: A Critique of Some Frequent Misconceptions of the Normalization Principle” (Perrin & Nirje, 1985). The first part, of which I was the principal author, deals with eight frequent misunderstandings. The second part, of which Burt Perrin was the main author, consists primarily of criticisms of some of Wolfensberger’s statements.

17 CONCLUSION

In the 1980s and 1990s, the Normalization principle has frequently been quoted in scientific studies, almost around the world. I have had the pleasure of invitations to Australia, India, Belgium, Germany, Switzerland, Finland, and Japan, and of return visits to the USA and Canada. In 1992, a collection of my papers and articles entitled *The Normalization Principle Papers* (Nirje, 1992) was published by the Centre for Handicap Research in Uppsala. In 1993, I wrote “The Normalization Principle: 25 years later” (Nirje, 1993) for the University of Jyväskylä, in Finland. It deals mainly with perspectives on services for adults, both the most and least severely impaired. It also takes up ethical issues and the relation of the principle to human rights. It was part of a larger project, aimed at renewing services for intellectually disabled adults in Finland. This year (1998) a five-year comparative study on the application of the Normalization principle in Sweden, Finland, and Japan will be completed. And just a few years ago, Gunnar Dybwad and Hank Bersani (1996) published *New Voices: Self-Advocacy by People with Disabilities*, which provided a forum for the voices of “intellectual” intellectually disabled persons from different parts of the world in the “People First” movement who expressed their right to self-determination.

In this lengthy exposé I have tried to point out the factors that led to the birth of an idea and the gradual construction of an instrument for analysis, which expressed a distinctive point of view. This point of view, I frankly think, tries to delineate in general and understandable terms the point of view of disabled people, wherever they might be. It articulates their demands for a normal day, a normal week, and a normal life in their communities. This concept I called the Normalization principle.

It seems as if this point of view, for more than a quarter-century now, has contributed to changes in views and policy direction. For example, institutions have gone from being seen as the normal and supposedly most efficient solution for dealing with the problems of mental retardation in society to being viewed as abnormal, as failing to improve, and even as worsening the situation of persons with intellectual
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impairments and disabilities. In the 1960s, did we ever hope that in the 1990s we would take this latter view and concomitant social developments for granted, with institutions even outlawed in some countries? Now, intellectually disabled persons hold international conferences to present their views and fortify their rights!

Obviously, I have reasons to feel cheerful about having been able to contribute to this new understanding, where the development of services for intellectually disabled persons now has less to do with national interests or financial priorities, religious creeds or beliefs, or political ideologies or prejudices. Today, services must be related to the demands for proper human development in the culture of a community where a child with an impairment is born, for now such a child is born with the same right to proper development as all other children in their community, society, and culture. Moreover, the child with an impairment has the right not to be exposed to, but, on the contrary, to be protected from neglect and abuse, ignorance and superstition, and segregation and extinction. I hope that the Normalization principle will turn out to be a useful instrument for social development in large parts of the world where the number of children born in the future will be much greater than in Sweden, Europe or North America.

I wish to conclude with a quote from my Jyväskylä paper (Nirje, 1993, pp. 16-17):

_The principle as instrument_

The Normalization principle with its eight facets or components engenders concerns in several directions or dimensions and is useful in many ways and at many levels, as it may relate to separate individuals, families, staff, professionals, community services or the society at large.

The first level obviously serves the individual with intellectual disability, and can be used by persons responsible in any way for him or her . . . "as an instrument for determining that which is appropriate both for raising questions and for finding answers. It implies, when in doubt how to meet a problem, how to advise, how to plan actions, what to do: compare the situation for any person, for example for yourself, with that of the person with mental or other handicaps, then try to see what is missing to possibly be able to determine what to do to shorten the gap between the two situations to let the handicapped person obtain the equivalent situation or one as close to it as possible. In that framework, we can use the following derivation: the Normalization principle means that you act right when you let the handicapped person obtain the same, or as close as possible to the same, conditions of life as you would prefer if you were in his situation" (Nirje, 1985; italics added).

On the second level, it serves the community as an instrument for the development or refinement of the educational and social services required and for an understanding of the needed training, support and cooperation of the various specialized staff. The principle helps in establishing goals and objectives, competencies and needs—both for the disabled persons and the staff.

The third level where the principle is useful is for the society as a whole, as shown by its use as one of the bases for legislation, for principal structures of services, and as an assist in providing a framework for laws, regulations and standards, even serving as an aid and guide in the work of the courts.

On a fourth level, the principle can also be seen as an instrument for understanding and analyzing—from a legislative, social, sociological, or anthropological point of view—the changes gradually taking place in the patterns of culture or conditions of life affecting not only persons with intellectual or other disabilities or other disabled, but also other groups in the society, such as immigrants, minorities, victims of crime, the elderly, etc. The principle as such is not culture-specific; but, being universal, is useful in any society, at any time, as a tool for description and evaluation. It can serve as a screen for the delineation and analysis of the social conditions of the intellectually disabled in Denmark or India, in Chile or China, in Germany (of the 1930s or today) or the USA, in Tokyo or Timbuktu, or in Outokumpu. (pp. 16-17)

Or, for that matter, it can be used in Ottawa at this conference on "Twenty-Five years of Normalization, Social Role Valorization and Social Integration," in the province where, some years ago, I myself stimulated our regional and district staff of the Ministry of Community and Social Services to properly apply the principle. It has been indeed nice to be back!
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A QUARTER-CENTURY OF NORMALIZATION AND SOCIAL ROLE VALORIZATION

Appendix

OUTLINE FOR A PLAN TO ATTACK INHUMAN CONDITIONS IN THE UNITED STATES' INSTITUTIONS FOR THE MENTALLY RETARDED

The following outline has divided the contents of the plan into four sections, which are inter-dependent. The first part indicates presentations of present conditions, the foundations of a criticism of the negative factors. Section two completes the criticism, stressing the positive factors that can help in making change possible. The third section tries to demonstrate the practical aims of the attack, indicating the direction to move. The fourth section gives the rationale for the aims outlined in section three and the criticism of sections one and two. In each section, only headlines are given and they have to be filled out by special study groups. The angles in the four sections are inter-dependent.

I To stress the dehumanizing situation in the back wards, the following points are presented:
A. Summary survey of all the scientific studies on the damage caused to the individual by institutionalization; the main findings should be presented in an authoritative way.
B. The point should be made that the dehumanizing conditions in institutions represent an imposed poverty and cultural deprivation, imposed by society with taxpayers' money.
C. The lack of personnel and of trained personnel, and what it means for the individual mentally retarded ought to be dramatized.
D. Defeat of the medical profession and the experts must be shown. The work for the mentally retarded must come out from under the authorities on mental health. The main task for the medical profession in this field is as experts in habilitation.
E. A condensed version of Mr. Allen's comparative study on US legislation on mental retardation should be made, and the lack of teeth in the laws should be dramatized.
F. The general difficulty in presenting the facts of life in the back wards to the general public must be pointed out. The difficulties in taking photos, making films, etc., preserve the general ignorance, assist the lack of concern, keep prejudices alive, and enforce the segregation, fears and anxiety.

II A critical survey of the factors in the present status that are of promise and can form a basis from which to start a new development.
A. The concern of the parents—not only in the US but all over the world. The symposium arranged by the International League of Societies for the Mentally Handicapped in Stockholm, June 1967, on the legal aspects of mental retardation and the human rights of the mentally retarded contains a series of recommendations and statements with a strong bearing on institutional standards and programs.
B. Existing good programs in the US, probably most to be found in private institutions, should be selected and presented, possibly also descriptions of programs and principles in some other countries.
C. Good staff training programs and their aims should be presented. It should also be stressed that the trained personnel have small chances to implement their education in the back wards, where the sheer numbers and the unsuitable facilities defeat their creative efforts.
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D. It should be stressed that professional experience that is modern and of high quality exists in the USA, and that more attention should be given to these experts. From the Allen study should be found that which he states as offering the most promise for an attack that can lead to practical results and give a reasonable hope for change.

E. NARC has to recommend a realistic legislative model that places the responsibility for institutions as close to the people as possible.

F. The mentally retarded’s right to a pension or minimum salary should be pushed with all energy. With the help of the retarded’s own guaranteed income, the financing and the development of proper and worthwhile institutions gets a firmer basis.

III The present dehumanizing conditions in the large wards of the big institutions; new facilities and new and more human environments—more conducive to the personal development of each single individual, to efficiency in educational efforts, and to realistic social integration—are created. To create humanizing facilities means to arrange them as close to the patterns and standards of regular home and school life as possible. These aims can be obtained through decentralization, differentiation and specialization. A prerequisite to eradicate the bad conditions in the back wards is a creation of new homes, schools and institutions to move the majority of the retarded to. Thereafter, the facilities in large institutions can be rearranged for a much lesser number than at present, who can profit from the rearranged facilities to better advantage.

A. Children should never be in large institutions or in institutions with retarded adults. For the children are needed: special hospitals for the profoundly retarded and for the severely and moderately retarded with multiple handicaps or complications; care homes—fairly close to a good hospital—with a home-like atmosphere and setting for the severely and moderately retarded, equipped with adequate educational and ADL training facilities. Consequently, the aim is to take small children out of large institutions.

B. School age children: The moderately and mildly retarded must have special schools and live in boarding homes and student hostels. School education has to be given in a regular setting, never in the framework of a large institution. The aim is consequently to take the special school children out from the institutions.

C. Adults who are mildly and moderately retarded and can work in the open market or in workshops shall be given hostels or smaller care homes, with suitable social training programs. They shall live in as normal a setting as possible, never in the framework of a large institution. The aim is consequently to take this large group out of institutions.

D. Some severely and moderately retarded with no important complications, but who cannot work in sheltered workshops, should be given smaller care homes with industrial therapy facilities. Thus, they will be able to live more close to their own homes. Consequently, the aims are to move a large group of this category out of institutions.

E. Adults who are profoundly retarded and severely or moderately retarded with multiple handicaps or complications should be given suitable special hospitals with adequate treatment and training facilities. Existing institutions could be rebuilt to suit the demands of these groups by using the wards for 80 to 100 people at present, for 15 to 20 in the near future. The aims are consequently to rearrange the present institutions to serve mainly for this category.

F. Old age! Some of the old retarded might with advantage be given the opportunity to move to smaller care homes, but some might be more at home in familiar surroundings and can stay in current institutions, which can be rebuilt into smaller home units. Consequently, the aim is to re-create the existing facilities to serve certain parts of this category.
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IV  The rationale for the aims and recommendations made in the previous parts.

A. All environments and programs have to be created with regard to the psychological requirements of the individual. A survey of the basic demands in this respect from the psychological experts ought to be made. Of special interest is a study by Henry Cobb on the retarded person’s attitude towards himself, a paper published in the proceedings of the Congress of the International League in Paris, 1966.

B. The specific educational requirements of the mentally retarded should be stressed:
   1) Special school and training school standards.
   2) The additional requirement of ADL, social training and leisure time activities.
   3) Education for mentally retarded takes place not only under 1 and 2 above, but also in the boarding home, which consequently has to have a setting as close to a regular home as possible.

C. The social integration aspects must be kept in the foreground:
   1) Homes, hospitals and institutions should be placed as close to the community as possible or preferably within the community and never be larger than the developments of natural inter-relations realistically will permit.
   2) The architecture and facilities within a home or institution should permit good patterns of social life within the institution.
   3) The programs of institutions shall contain many points of contact with life outside the institution.
   4) For some of the retarded the programs should aim at preparing and assisting them for a life outside the institution.

D. Mainly irrespective of the degree of the handicap, the programs for the mentally retarded should aim to give them possibilities to achieve more independence, to experience more individual dignity and regard and to obtain more self-confidence. The programs should feed them more of the normal motivations of regular human life and be more attentive to their own wishes and demands.

V  With the points made in sections I and IV above, the following tentative recommendations are made:

1) Coincidental with the publication of the President’s Panel Study on Institutional Conditions, a first class TV documentary ought to be shown, contrasting present conditions with examples of good programs.
2) The idea of creating a NARC Robert F. Kennedy fund for human rights in institutions for the mentally retarded should be taken into consideration.
3) A national public conference of experts and parent representatives could be arranged, concentrating on the following issues:
   - Why has all the scientific research on institutional damage not been a cause for positive action?
   - Why has the medical profession been defeated in this field?
   - Why have the voices of the modern experts not been listened to?
4) The conclusions of the Allen paper should be dramatized with a NARC proposal for model legislation.
5) The meaning of the lack of personnel for the life and development of a child in a large back ward should be dramatized. The ignorance and lack of concern of society show themselves through the lack of effort to provide personnel, who could give the mentally retarded the personal attention and concern needed.
6) The positive practical aspects of sections III and IV should be dramatized by presenting the possibilities for individual development of the mentally retarded. A positive appreciation of the mentally retarded is a prerequisite for changing the image of the retarded in the eyes and minds of the general public, which precedes a willingness to positive action.

Bengt Nirje
June 12, 1968