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Abstract

Robert Perske is an ally of people with disabilities in the U.S.A. He and his wife, Martha, collaborated on two major reports to U.S. presidents; one to President Carter and one to President Nixon. In this article he writes from the basis that we overprotect people who have disabilities and that to "deny any person their fair share of risk experiences is to further cripple them for healthy living". He cites new (the article was written in 1972 but is still timely) attitudes towards risk and people with disabilities in Scandinavia and asks is it applicable to the North American scene. Since we in Australia learn much from our American neighbours, this article is of value. It looks at how we must allow for people's individuality and growth potential. It concludes with the statement, "there can be such a thing as human dignity in risk, and there can be a dehumanising indignity in safety!"

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THE DIGNITY OF RISK AND THE MENTALLY RETARDED

by

Robert Perske

Director of Chaplaincy Services
Kansas Neurological Institute and Staff Affiliate,
The Menninger Foundation,
Topeka, Kansas

Risk and the Retarded

In the December, 1969, issue of McCall's, S. I. Hayakawa, one of the nation's leading authorities on semantics, made the statement that there are hidden meanings in the word "mental retardation." When this word is used, the thought "how tragic" automatically flashes into the minds of many hearers. This is a paradox to Hayakawa since one of the happiest members of his family is a teenage mentally retarded son named Mark.

There are other hidden meanings in the term "mental retardation." For many who work with the retarded, this term triggers such action words as "protect," "comfort," "keep safe," "take care," and "watch." Acting on these impulses, at the right time, can be benevolent, helpful, and developmental. But, if they are acted upon too intensely, or if they are used exclusively without allowing for each retarded person's individuality and growth potential, he becomes overprotected and emotionally smothered. In fact, such overprotection endangers the retarded person's human dignity and tends to keep them from experiencing the normal taking of risks in life which is necessary for normal human growth and development.

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Wolfensberger (1969), in his historical study of American attitudes toward the mentally retarded, has shown that there was a period of history in which we saw the mentally retarded as "objects of pity." But this period did not last long; soon, pity degenerated into loathing as the retarded began to be perceived as a "menace to society."

Wolfensberger's history forces us to ask a rather piercing question: Why has it seldom occurred to us that a mentally retarded man or woman can be seen as a courageous person? There are those who are; but what has kept us from seeing them all as such?

In 1966, a ten-year-old, severely retarded boy named Billy, wondered away from the midwest institution where he lived and became lost in the woods that skirted the institution grounds. The temperature was below freezing. All off-duty personnel were called back to the institution to form emergency parties to search for the boy. Two moderately retarded teenage boys, Ray and Elmer, asked a staff member if they could search for Billy, too. The staff member "moved through channels," and, after some time, received approval for the boys to join in the search, and they found the lost boy! At a later program, the superintendent gave Ray and Elmer special recognition and letters of commendation. By this time, many of the staff were haunted by the fact that there were 35 adolescent boys and 40 girls in the institution who functioned every bit as well as Elmer and Ray. Since this particular wooded area is not terribly large, they might have been mobilized more efficiently and quickly than the staff.

All this helps one to see the many ways in which the mentally retarded can be denied their fair and prudent share of risk-taking. Many who have worked in the field of retardation for any length of time can be aware of the clever ways in which all of us have built the virtually total avoidance of risk into the lives of the mentally retarded by limiting their spheres of behavior and interactions in the community, jobs, recreation, relationships with the

opposite sex, etc. Even buildings constructed for the benefit of the retarded are filled with things designed to help the residents avoid risk. Fortunately, there is a growing awareness and many beginning efforts in America to allow the retarded to assume a fair and prudent share of the risk, commensurate with their functioning.

Some New Attitudes Toward Risk and the Mentally Retarded in Scandinavia

With the backing of a Rosemary Dybwad International Award from the National Association for Retarded Citizens, it was my opportunity to travel to Scandinavia and study the ways in which Swedish and Danish people have given human dignity to their mentally retarded citizens. During this study, one of the most exciting things I observed was the many new, and different ways these people are attempting to put reasonable risk back in the life of the retarded persons in their midst. Though these attempts are still rather new and somewhat isolated, sound principles underlying what is being done seem to be developing.

The beauty of it all is that new attitudes toward risk seem to be one of the quite unforeseen by-products of Denmark's and Sweden's crash programs for the mentally retarded. It is my hunch that neither the Danes nor the Swedes completely planned or predicted this new and fresh attitude when Denmark passed the "Act of 1959" (Bank-Mikkelsen, 1969), and Sweden enacted the "Normalization Law" in 1968, (Nirje, 1969).

In this paper, I will present first-hand observations of incidents where workers in these two countries allowed their retarded to experience a reasonable amount of risk. Since we, in America, are beginning to struggle with this problem as well, it is hoped that these incidents will illuminate and clarify the directions and attitudes we may choose to take in the future.

Programming Risk-Taking Experiences in Scandinavia

Some Scandinavian workers with the retarded are developing innovative ideas to literally "push the retarded out of the nest" as a means of finding new growth. Such experiences in a number of areas of living are illustrated below.

Normal Risk in Community Experiences

Bengt Nirje, the Secretary General (Executive Director) of the Swedish Association for Retarded Children, has developed as a side interest the formation of youth clubs in Stockholm, where both college students and mentally retarded youths serve as co-workers. In four years, the first Flamlattsklub has grown into 24 clubs. Kept to approximately 20 members each, these clubs plan a wide range of recreational and educational activities. To be a member in full standing a retarded person must first learn to find his own way from his home to the clubroom in the center of downtown Stockholm.

Nirje has attempted to build into each club something he calls "hidden social training." Members are required to do for themselves what they have never done before. For example, a group may travel for a special program to a section of Stockholm where they have never been before. When the program is over, they are expected to find their way home alone, even though this involves the struggle of asking questions of strangers, getting one's own direction, finding the right bus or subway, etc. At another time, a day's outing at a particular amusement area may be planned and then the leaders may be "called away," leaving the retarded persons to entertain themselves.

There are a variety of experiments where mentally retarded persons are allowed to live in apartments in the city. The degree of supervision while living alone in these apartments ranges from intensive to none. In a boarding school outside Vingaker, this period

of self-reliance may amount to a weekend after which the mentally retarded return to the school to evaluate their experiences. In Flen (also in Sweden), institutionalized persons move into a rented hotel for a period of training and supervision. Later, they move into apartments and live alone.

The different plans for programming experiences of being left alone in a city or of being placed in a strange apartment varies with the region and the agency, but I was amazed at the great number of such programmed risks that have been developed.

Normal Risk in Industry

Workshop personnel anywhere can be very imaginative in designing jigs and fixtures or in modifying industrial equipment, either to simplify an operation, or to make it safe. In either case, such ingenuity may be the critical element in opening up many tasks to severely impaired persons. However, in our good intentions, one may go too far, and once more lose sight of individual differences in the capabilities of the retarded. To reshape a task that might be performed by an ordinary industrial worker solely because a retarded worker is to perform it is dehumanizing if the retarded worker is capable of performing the same task on the same equipment as safely and/or as well as the industrial worker.

The general movement from basket weaving, ceramics, pot-holder making, and other occupations of a handcraft variety, to productive manufacture of useful and marketable items has served to expose many retarded Scandinavian persons to the normal risks found in any industry. For example, in the Orebro district in Sweden, I saw a nineteen-year-old mongoloid man sitting at a large punch press with all its mechanical shafting and mechanisms standing ten to twelve feet high. He pushed a button and a mass of metal came hurtling down on the press plate with a thud. There would not be much left of his hand if it got in the way. This type of operation was also observed in Gothenburg, Uppsala, and in a Danish Workshop in Farum.

Throughout these two countries, one can see retarded persons operating heavy-duty punch presses, drills, and saws while they do simple repetitive operations on a Volvo automobile finder, on brass fittings, or on Danish Modern furniture, to name only a few. It was noticed that the risks these persons took were normal for industry in these countries.

In Örebro, the Frykstagården workshop contains a work force of 15 deaf, mentally retarded adolescents and young men who turn out routine machined items on heavy duty lathes. Their foreman, Karl Bargquist, felt the need to tell me: "That's not easy, you know. A regular worker can hear when the machinery is going to break and fly in his face. These people can't hear. So, I teach them to watch things with an alert eye."

There was danger here! In fact, there was enough danger to put great fear in the heart of any worker with the mentally retarded who tended to be over-protective. But, the remarkable thing about these workshops was that their foreman expected their workers to be safe. For the most part, these persons lived up to the expectations of the leaders. It could be conjectured that there would have been tragic consequences if the foremen expected the retarded workers to get hurt.

Normal Risk in Heterosexual Relationships

In healthy human beings attempts to build close, creative human relationships, there is always a risk and a chance for failure and pain. We have yet to completely evaluate what we do to the human dignity of a mentally retarded person when such relationships are denied. Now, we are beginning to wonder about our "safe" segregation of men and women — sometimes for life.

Bo works in an assembly line for TV terminal strips at the Frykstagården workshop in Örebro. Approximately 26 years of age, he suffers from spastic paralysis, but has an ingenious way of

putting metal pieces into plastic parts using a vice (others can do the same operation much more readily with a hammer). Marie, age 21, works elsewhere in the line; she is spastic also. Bo and Marie look forward to being together in the lunch room. Sara Wendahl, the social worker, pointed them out to me, saying, "they're in love." Slowly these two persons, with professional help, were working out plans for the day when they could live together and make a closer relationship. Because of the spasticity of both of these persons, sex could hardly be a very large issue, but there seemed to be so many other creative possibilities between them. It was obvious that everyone respected these two and their attempts to find one another.

Older men and women with many years of institutionalization behind them are given the chance to attempt a life together when the chance for failure is not terribly great, though in any close human relationship there must be some risk. Many human beings choose to live out their lives keeping distance between themselves and others, a fact also true of many of the mentally retarded. But there are some who would not choose isolation. Throughout Denmark and Sweden, there seems to be a movement away from dormitories of men and dormitories for women, with a "never-land" in between. Instead, the tender, patient, sensitive building of closer human relationships under supervision was observed in many areas of both countries. The healthy, carefully evolved decisions of these retarded persons were honored and regarded by the helpful professionals as being within the limits of normal human risk.

Normal Risk in Building Design

For years, in both Scandinavia and the United States, when architects were contracted to build a facility for the mentally retarded, they automatically drew up plans for a "heavy-duty" and a "super-safe" facility. In both countries, the building codes have reinforced this attitude. But now there seems to be a struggle to change.

If a small "family" of mentally retarded persons are to be housed in a two-story home, some local governments will demand an outside fire escape, special exits, expensive fire detection systems, and special electrical wiring and plumbing, to name only a few restrictions. If a professional attempts to move his own family of the same size into the same two-story home, these "special" standards do not apply. In both America and Scandinavia, we are becoming aware of the fact that the most human facilities for the mentally retarded are those that have not been built for the mentally retarded. Instead, they are properties built for other purposes and later they are rented to agencies for the mentally retarded.

Sweden and Denmark are now struggling to break this tradition, and have already made much progress in this direction. New institutions for the mentally retarded are being constructed more and more the way homes for normal, happy human beings are constructed. They are being designed with plenty of glass, many doors to the outside, and lots of brightly colored fixtures and furniture. Beautiful hanging lamps can be seen everywhere, and nobody seems to swing from them — because it is expected that no one will. This new architecture is saying some powerfully hopeful things to and about human beings who happen to be mentally retarded.

Sweden has a penchant for spiral staircases. They are rather beautiful but dangerous. One can stand at the top of one of these staircases and look down at the inner pole and see nothing but a spiral of space curling around and around. Walk down on the wrong side of one of these staircases, and you can be maimed or killed! Yet, such staircases can now be seen time and again where the mentally retarded live.

We are now beginning to learn that there is such a thing as the "language of a building" (Wolfensberger, 1969). We do "say something" to the mentally retarded person who lives in the building that we build for them. We can say: "We will protect you and comfort you — and watch you like a hawk!" Or we can say: "You are a human being and so you have the right to live as other

humans live, even to the point where we will not take all dangers of human life from you."

The New Scandinavian Attitude Toward Risk and the Mentally Retarded: Is It Applicable to the American Scene?

What is it that we in America who work with the mentally retarded can learn from Sweden and Denmark's attitude of allowing the mentally retarded to experience normal risk? Before an answer is attempted, it might be well to recall how much they have learned from us. In an endless range of situations, they can quote American experts — even to the point where a Swedish man was able to inform me that Henry Ford called his first automobile the Model "T", because it was the first "tempo" manufactured car. These people seem to be the skilled implementers and appliers of a wide range of knowledge from other lands. They seem to do it in the same way that they gather raw materials from all over the world and then design and manufacture some of the most excellent products on the face of the earth. Most of these ideas about risk-taking were not new with the Scandinavians. We have theorized about such things for years and years, but in many cases, they implemented what we often only felt or talked about.

It would be spurious to try to make Swedes and Danes out of Americans. We gave up such "missionary" action years ago. But it would be expedient to watch the hopeful struggle in which the Scandinavians are involved, focus on their attitudes, and see which would be compatible with healthy American life and which would not. God knows, we cannot continue the type of over-protection we usually give the mentally retarded in our country.

The world in which we live is not always safe, secure and predictable. It does not always say "please" or "excuse me". Everyday we wake up and live in the hours of that day, there is a possibility of being thrown up against a situation where we may have to risk everything, even our lives. This is the way the real world is. We must work to develop every human resource within us in order to

It is my firm belief that we now need to insure this dimension of human dignity for the mentally retarded and prepare them for facing real risk in a real world. Where many of us worked overtime in past years to find clever ways of building the avoidance of risk into the lives of the mentally retarded, now we should work equally hard to help find the proper amount of normal risk for every retarded person. We have learned; there can be such a thing as human dignity in risk. And there can be a dehumanizing indignity in safety!

prepare for these days. To deny any retarded person their fair share of risk experiences is to further cripple them for healthy living.

A book has recently been published in German that could haunt us all (Teufel, 1960). It graphically describes the human responses of children and adults in a 700-place institution at Stetten, Germany when, in 1940, two gray buses with windows painted gray drove up to the institution for the first of many trips. The driver presented a list of residents who were to be "transferred," and then drove them off after saying to a worker: "Soon there will be seventy-five less idiots in the world." During an extended period of time, 322 of the 700 were driven off to be gassed and cremated. But, the most interesting thing in this account is that it makes one aware of the fully human reactions of these people in the face of this risk.

The ambulatory persons became deeply concerned for the non-ambulatory, knowing they had little chance to fend for themselves. Many used their best wits to scout and plan special hiding places to which they fled every time they saw the buses coming up the road. One boy instinctively ran to his hiding place when the critical time came. He then returned after the buses were gone saying, "They didn't catch me, I'm smarter than they." Karl fought with the driver and ran away shouting, "I'll hang myself before I'll die like that." Richard, who was paralyzed, knew he did not have a chance; with calm and purpose he gave his pocket money and watch to his closest friend. He discussed the situation with his housefather, and they prayed together as he made himself ready to die like a man with dignity. "Cool" Emily calmly got into line on the day her name was called and walked to the bus. But, as she came near the door of the bus, she calmly walked right on by and nobody even noticed. Later, when the bus was gone, she returned to the institution and busied herself with her assigned task of scribbling steps. All this points up how mentally retarded persons may, can, will and should respond to risk with full human dignity and courage.