

The Dignity of Risk and the Mentally Retarded

ABSTRACT. In Denmark and Sweden, there is a growing interest in granting mentally retarded persons their fair and prudent share of risk-taking in their daily living. Denying the mentally retarded exposure to normal risks commensurate with their functioning tends to have a deleterious effect on both their sense of human dignity and their personal development. In addition, the removal of all risk diminishes the retarded in the eyes of others. The author seeks to show how appropriate and reasonable risk-taking can and should be worked into the daily living experiences of the mentally retarded in America.

Robert Perske

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 many minds. 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, the retardate becomes overprotected and emotionally smothered. In fact, such overprotection endangers the retarded person's human dignity and tends to keep him from experiencing the normal taking of risks in life which is necessary for normal human growth and development.

Wolfensberger (1969) has shown that there was a period of history in which many saw the mentally retarded as "objects of pity." 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 have we seldom thought that a mentally retarded man or woman can be courageous? Some are, but what has kept us from seeing them all as such?

A severely retarded 10 year old named Billy, wandered away from an institution where he lived and became lost in the woods nearby. 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. As it turned out, Ray and Elmer found the lost boy. The superintendent gave them special recognition and letters of commendation. As a result of this incident, the staff became more aware

of the 75 other moderately retarded adolescents (boys and girls). These teenagers might have been mobilized more efficiently and quickly than the staff had they not been denied their fair and prudent share of risk-taking.

Many who have worked in the field of retardation for any length of time are aware of the clever ways in which virtually total avoidance of risk has been built 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 designed to help the residents avoid risk. Fortunately, there is a growing awareness of these facts, and many beginning efforts are being made in America to allow the retarded to assume a fair and prudent share of risk, commensurate with their functioning.

Scandinavia's Attitudes Toward Risk and the Mentally Retarded

With the backing of a Rosemary Dybwad International Award from the National Association for Retarded Children, the author traveled to Scandinavia to study the ways in which Swedish and Danish people have given human dignity to their mentally retarded citizens. During this study, many new and different ways were observed in which the Swedes and Danes were attempting to put reasonable risk back into the lives of the retarded. Though these attempts are still rather new and somewhat isolated, sound principles underlying what is being done seem to be developing.

It seems that a new attitude toward risk may be one of the unforeseen by-products of Denmark's and Sweden's crash programs for the mentally retarded. The author speculates 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, the author will present first-hand observations of incidents where workers in these two countries allowed their retarded to experience a reasonable amount of risk. It is hoped that these incidents will illuminate and clarify the directions and attitudes Americans 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 formed youth clubs in Stockholm, where both college students and mentally retarded youths serve as co-members. In 4 years, the first Flamslattsklub 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 "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; 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 retarded return to the school to evaluate their experiences. In Flen (also in Sweden), institutionalized persons move into a rented hostel for a period of training and supervision. Later, they move into apartments and live alone. The 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.

Normal Risk in Industry. Workshop personnel anywhere can be very imaginative in modifying industrial equipment, either to simplify an operation, or to make it safe. Such ingenuity may be the critical element in opening up many tasks to severely impaired persons. However, we must not 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 exposed many retarded Scandinavians to the normal risks found in any industry. For example, in the Örebro district in Sweden, a 19 year old mongoloid man was sitting at a large punch press with all its mechanical shafting and mechanisms standing 10 to 12 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, retarded persons were seen operating heavy-duty punch presses, drills, and saws, while they did simple repetitive operations on a Volvo automobile fender, 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 Frykstagarden 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 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 enough danger here to put great fear in the heart of any worker with the mentally retarded who tended to be over-protective; but the foremen of these workshops 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.

Bö works in an assembly line for TV terminal strips at the Frykstagarden 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 vise (others can do the same operation much more readily with a hammer). Marie, age 21, works elsewhere in the line; she is spastic also. Bö and Marie look forward to being together in the lunch room. The social worker pointed them out, 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 attempt 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. There are some, however, who would not choose isolation. Throughout Denmark and Sweden, there seems to be a movement away from segregated dormitories for men and women. 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 helping 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. 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 "say something" to the mentally retarded persons who live 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."

Is the Scandinavian Attitude Applicable to the American Scene?

What can Americans learn from Sweden's 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. The Scandinavian people seem to be skilled implementers and appliers of a wide range of knowledge from other lands. 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. In reference to risk-taking, most of these ideas were not new with the Scandinavians. Americans have theorized about such things for years, but in many cases, the Scandinavians had implemented what we often only felt or talked about.

It would be valuable for Americans 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. 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 there is a possibility of being thrown up against a situation where we may have to risk everything, even our lives. This is the *real* world. We must work to develop every human resource within us in order to prepare for these days. To deny any retarded person his fair share of risk experiences is to further cripple him for healthy living. Mentally retarded persons may, can, will, and should respond to risk with full human dignity and courage.

It is the author's 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 have 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. It is hoped that this paper has helped to illustrate that there can be such a thing as human dignity in risk, and there can be a dehumanizing indignity in safety!

References

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About the Author

Robert Perske, Executive Director of Greater Omaha Association for Retarded Children, is the 1969 recipient of the Ann Fenn Memorial Award which is given each year by the Rosemary Dybwad International Awards Committee. The award money was used to finance this study tour in Sweden and Denmark.