



## Beginnings and Endings: The Quality of Life for Young and Old

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...It was in 1938, exactly fifty years ago, when I b\_ working at Letchworth Village, one of the older New York State mental retardation institutions, on a study of young residents who had been involved in delinquency in the community. I still remember my amazement to discover a procedure which gave me my first clue that those confined in that institution were treated in ways which at first seemed grotesque until it began to dawn on me that these people were not considered to be quite human beings like the rest of us. What I observed was simply this: Letchworth Village had one of the first EEG laboratories and the entire population was being screened. Because some of the residents were restless, the laboratory technician positioned each on a table and to distract their attention a Mickey Mouse film was shown on a small screen within view of the resident. The machine was shut off as soon as the examination was finished and that might be in the middle of the film, then turned on for the next resident. Once the film was finished it simply was played backward for the next person instead of being rewound. The technician, a kindly older man said to me, "they wouldn't know the difference anyhow." And so Letchworth Village in those days had for the people 'who wouldn't know the difference anyhow' dormitories overcrowded with 100 beds and 125 children sleeping in those 100 beds. I also actually saw in those early days an incontinent man in a small room lying in a box of sawdust. There was no bed. Still, Letchworth Village had a large medical staff, a well staffed social service department, and was famous for its psychological research laboratory....

At the close of the 1950 's, Governor Clement of Tennessee came to the end of his tenure and one day told his staff that he would like to have a nice state building named after him. Somebody suggested that Cloverbottom, the state institution near Nashville, needed a new building for severely, multiply handicapped patients. The idea appealed to the governor and he instructed the

staff to spare no money. Shortly after the building was completed I visited there and the superintendent, a well-known psychiatrist with experience in other mental retardation institutions, proudly took me to the new building. It was filled with cribs made on three sides of the best Tennessee marble, with an aluminum wire mesh front that opened. The crib stood high on four steel legs so the staff did not have to bend over. (And all that was needed was another marble slab on top to change the crib into a tomb.) But then the psychiatrist showed me the main feature: He called an attendant who came with an hydraulic jack on wheels, quickly lifted the rubber mattress with the patient on it, and rolled the jack to the middle of the large dormitory. There was a gangway there with low walls from which streams of water could be turned on so that as the jack rolled through, the patient was bathed, untouched by human hands. ...The psychiatrist smiled with satisfaction, turned to me and said, "This is our 3-minute car wash!"

Why have I told you these appalling vignettes of past institutional life? Because the system that created these dehumanizing arrangements is still with us today. To be sure, very considerable changes have been made, but some of the senior staff who worked under those conditions are still on the job, and we need to be mindful that by and large it was only as a consequence of outside pressure, especially from the courts, that the system finally and reluctantly discontinued some of these practices....

Again I say that we have made tremendous progress since those days, but to understand the persistent critics of efforts to safeguard and enhance the quality of life of *all* persons with developmental disabilities, one has to be aware of this background and the tenacity with which a large faceless bureaucracy holds on to established routines, to fixed prejudicial views, to a pecking order which kept the institutional resident firmly fixed to the bottom of the pile. Superintendents came and went but the central office bureaucracy is ever present and exercises its power by its sheer permanency. Thus a new question arises: What safeguards will we need to protect the integrity of our new community programs? Here is a real challenge to the Commission on Quality of Care.

I was very glad when the program committee asked me to address my remarks today to the "Beginnings and Endings of the Life Cycle with Reference to the Quality of Life" because this reflects problems to which I have addressed much of my work.

Let me start with the ending - the older person with mental retardation. There we encounter a remarkable phenomenon: Until as late as the sixties not only old age but adulthood in mental retardation was simply not recognized or at least not acknowledged. At the half century mark, in 1950, mental retardation was a child problem and since we have in this audience so many workers from the field of mental health it should be added that mental illness on the other hand was seen at that time as an adult problem. ...And to this must be added that truly unbelievable misunderstanding in the professional field with regard to the confused and confusing misinterpretation of the concept of mental age, based at that time solely on performance on an intelligence test. Thus parents were told that their son or daughter had a mental age of five and would always be like a five-year-old child and behave accordingly. So they hid at home from public view their 5 foot 2, 140 lb. son or daughter with Down Syndrome, believed to be forever a 5-year-old. Those of us who were working in or visiting mental retardation institutions saw the truly incredible spectacle of a building with 40 or 50 grown up men and women dressed like children and engaged in children's activity, spending their day outdoors in playgrounds with equipment designed for children.

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In 1960 Dr. Edward L. Johnstone, the President of the Woods Schools and a great pioneer in our field, arranged an exciting conference entitled "Outlook for the Adult Retarded." He assigned to me the topic "Developing Patterns for Aid to the Aging Retarded and His Family." This, I believe, was the first time the term "aging" was used on the national level in the field of mental retardation....

But what has been the story at the other end of the spectrum - what about the quality of life for the very young? One aspect brings us right back to the 1940's and '50's, to the beginning of the parent protest movement which in turn ushered in the long overdue reform in mental retardation. Again we need to be reminded that the parents protested and organized on behalf of their children's exclusion from schooling and any type of vocational training. ...But what about the infants, the children of pre-school age? Many of their parents were still in the dark about their child's impairment and those who did suspect that something was wrong were likely told by their physician 'give him time, he'll outgrow it' or "she'll catch up, let's not do anything."

The Kennedy Foundation (1971) showed a film depicting the actual story of an infant with Down Syndrome whose parents refused to give permission for needed and relatively minor surgery, and so the hospital, bowing to the parents wishes, starved the child to death over a period of 15 days. Undaunted by this strong effort of the Kennedy Foundation to put this medical practice of killing babies with Down Syndrome into question, Joseph Fletcher (1972) reformulated his contrary thoughts in an article called "Indicators of Humanhood - A tentative Profile of Man," published by the distinguished and most influential *Hastings Center Report*. He stated that an IQ below 20 would characterize a non-person, an IQ under 40 a semi-person - with the implied notice that a non-person's life could be terminated without consequences, ethical or otherwise.

His was by no means a lone voice. In 1975 the same

*Hastings Center Report* published an article by Dr. Anthony Shaw, Professor of Surgery and Pediatrics, entitled "Defining the Quality of Life" in which he went Joseph Fletcher one better (1975). The article presented a formula to determine the quality of life as follows:  $QL = NE \times (H+S)$  meaning quality of life equals native endowment multiplied by the sum of the contribution to be made to the individual under question by his home and family and by society.

You may wonder what earthly significance such a formula could have, but unfortunately, it was used by a team of physicians at the Oklahoma Health Service Center to determine which infants born with spina bifida should receive corrective surgery and which infants should remain untreated and left to die. This was described in detail by R.H. Gross and others in an article published in *Pediatrics*, the official journal of the American Academy of Pediatrics (1983). When it was revealed that the medial team at the University of Oklahoma indeed used such a selection process to determine life or death for children with spina bifida, a lawsuit was filed in federal court which has not yet been decided.

But even this legal action before a federal court did not keep Dr. Anthony Shaw from publishing in the current April/May 1988 issue of the *Hastings Center Report* an article entitled "QL Revisited" in which he defends and elaborates on his Quality of Life formula for what he calls moral decision making in medicine. With



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all due deference to the surgical skills of Dr. Shaw, i cannot accept any validity for an assessment of the native endowment of an infant, or more precisely, of a newborn infant. I do not know of any clinical psychologist who would dare to do that but for the very rare cases of conditions such as total anencephaly. And only the White House astrologer would dare make a prediction at that time of the contribution the home and family and society at large would make in the future to the newborn infant's quality of life. You may say, "But who will listen to this kind of nonsense?" I am sorry to say: the courts of this country will listen - they still think that the medical profession by some ordainment from above are the proper judges of human conduct and behavior. The standard of living (and I purposely do *not* say the quality of life) of the medical profession is on a distinctly higher level than that of the general population. Are we to accept without question what they determine as quality of life? What chance has a mother on welfare, what chance has a black woman to pass muster for the Oklahoma physicians about the mother's contribution to her child with a handicap?

On the positive side we have seen of course in recent years on behalf of infants and young children with disability a rapidly growing number of programs referred to as "Early Intervention". Without doubt they provide a very significant assurance toward a better quality of life but as yet they are new additions to an old system, and in a period of budget cutting, service consolidation and fund withholdings, they are greatly at risk. It is for that reason we must be concerned with the value judgments of the false prophets of quality of life I have presented to you. If they raise enough doubts in the minds of the budget cutters and program consolidators, early intervention programs in the field of severe disability may become endangered species. Furthermore, if such negative assessments of the quality of life of severely damaged infants gain acceptance, must we not be prepared to face a clear and present danger for older more severely incapacitated persons whose quality of life does not come up to some medical group's minimum standards? A slippery slope indeed, but note the words "*if* such negative assessment of the quality of life of severely damaged infants gains acceptance." This if must not happen, we need to counter those negative judgments I have related to you with our own accounts of the growing achievements of even persons with most severe

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limitations. But we must do so with one important qualification: what all of us (or at least almost all of us) used to speak of as *our* successes, we must now clearly describe as *their* successes, with help from us. (And, if we are honest, we have to add 'at times in spite of us'.)

I continue to be an optimist. We are making progress, we are gaming ground and I still believe in some lasting verities which have increasingly fashioned my approach to serving persons with a handicap. Some of you have heard them before but they bear repeating:

In dealing with the problem of human growth and development, one should never say "never" - there is always change, the dynamics of which so far have not become clear to scientific exploration - no one can predict as a human being is born, where the limits of the person's growth and development will be. I reject and resent the arrogance of bureaucratic and professional workers who predetermine another human being's potential.

In searching for solutions to human problems, I am more and more impressed with the overwhelming importance of one's personalized environment - for the child, the family; for the adult, in addition to his family, his own living space. Thus, home support looms ever larger on my list of priorities....

Much of my most significant learning in the field of disability I owe to parents of children with handicaps. But more and more I am convinced that we must listen to a far greater degree to the individuals with handicaps. For a long time we thought those with more severe disability could not learn; now we know we did not yet know how to teach. Similarly, what we call the inability of persons with severe handicaps to communicate, may well be our ineptness in listening. So we

must learn to listen, and while this is not easy for those whose hearing is going sour, try we must

Self-advocacy has now become a worldwide movement, small in numbers as yet, but strong in resolve. And I dare predict that the Commission on Quality of Care for the Mentally Disabled (by the way, is it not time for you to change that language and acknowledge that you strive to deal with *persons*, not labels?) I dare predict that the Commission will increasingly come to listen more to those persons and less to experts whose assumptions and presumptions (mine included) have so often turned out to be wrong or at least of passing value only.

A few months ago the local ARC in Northampton, Massachusetts, asked me to speak to them. I obliged because it is my continuing contact with small, local units that keeps me posted in ways national newsletters cannot convey to me. But great was my surprise to find that at least half of my audience were self-advocates, many of them former residents of the Belchertown State School. After my presentation they had their say and their message was loud and clear: They had not left the Belchertown institution (they did not use quite as polite an expression) only to find annoying restrictions and silly regulations in their community programs. Their speech was halting and at times unclear, but not so their meaning and their earnest desire to help create a better life for themselves.

On second thought, with all the problems we have with the concept of care, how about changing your name to State Commission for Quality of Caring?

[The bibliography prepared for this presentation is available from Professor Dybwad at the Heller School, Brandeis University, Waltham, Mass., 02254.]