FROM FEEBLEMINDEDNESS TO SELF-ADVOCACY A HALF CENTURY OF GROWTH AND SELF-FULFILLMENT

by Gunnar Dybwad, Ph.D.

Heller School, Brandeis University

Presented at the 118th Annual Meeting of the American Association on Mental Retardation

June 2,

1994

Boston, MA

NOV 1 0 1994

Minnesota D.D.

RECEIVED

FROM FEEBLEMINDEDNESS TO SELF-ADVOCACY A HALF CENTURY OF GROWTH AND SELF-FULFILLMENT*

by Gunnar Dybwad**

I am most grateful to the program committee for giving me this opportunity of sharing with you in a personal retrospective developments over the past 54 years in our field under the title From Feeblemindedness to Self-advocacy, A Half Century of Growth and Self-fulfillment. Obviously, this will reflect my own experience, the persons with whom I worked and who guided me and most decidedly also my mid-western and later my eastern location.

I have just used the pronoun "my" but it really should have been "our" because my wife has shared these many years and was my constant guide, critic, travel companion (she always reminded me in what country we were working), and above all, source of inspiration. To prepare this presentation without her was difficult indeed.

It was 54 years ago that I had the opportunity to participate in the 64th Annual Meeting of AAMD in 1940 in Atlantic City. I presented a paper which reflected in its title the language of those days: The problem of institutional placement for high grade mentally-defective delinquents, subsequently published in the American Journal of Mental Deficiency. (Dybwad, 1941)

At the time, my wife and I were working in the clinical department of the New York State Training School for delinquent boys in Warwick. Among recent admissions there were a few boys who had been adjudged delinquent but who seemed to be too backward in their development to hold their ground in our generally rather aggressive, street-wise institutional population. Might they not do better in the neighboring state institution for the feeble minded at Letchworth Village?

My prior contact with such a program had been a day's visit in 1936 at the Wayne County Training School at Northville, Michigan, the only such institution run by a county and with admissions limited to children of school age with a mild degree of mental deficiency. It had rather good physical facilities and an excellent education program under Dr. Thorlief Hegge originally from Norway, and a world-famous research department headed by Robert

---

* Presented at the 118th Annual Meeting of the American Association on Mental Retardation

** Professor Emeritus of Human Development, Brandeis University

Strauss and Heinz Werner, early pioneers in the as yet largely unrecognized area of learning disabilities. I was much impressed and when two years later I had to select a field work placement for my studies at the New York School of Social Work, I selected the Letchworth Village Institution .

I was in for quite a culture shock. At the Warwick institution, New York State provided for the juvenile delinquents cottages with a small dormitory and a number of single rooms, a small dining room in each cottage, modern educational and recreational facilities, weekend visits to the home and from the family, facilitated by the institutional bus and a very active social service staff in New York City in addition to clinic workers at the institution. In contrast, I found at Letchworth Village for that vulnerable population dormitories with 100 beds and 125 children in those beds. On one adult ward I saw incontinent "untidy" men lying in boxes of sawdust. Throughout the institution there was rigid discipline. Only a small number of children went to a school program ~ the rest of them marched every morning and afternoon with hoes and other farm implements for a full day of slave labor on the institutional farm. Nobody was concerned that this was a clear violation of the United States Constitution which provided since 1865 that "neither slavery nor involuntary servitude except as punishment for crime whereof the party should have been duly convicted, shall exist in the United States." Here was my first object lesson that persons committed to a mental deficiency institution were denied the protection of the law, a lesson I would have to face time and again in subsequent years.

What was the viewpoint of AAMD to the field in general and toward institutional developments in particular? Obviously, absent any formally adapted resolutions, this is hard to determine. But to match my own historical viewpoint, at least to some extent with viewpoints expressed at AAMD's annual conferences, I arbitrarily reviewed the AAMD presidential addresses at the beginning of each decade from 1930 to 1990 to get a measure of consistent commentary.

At the 54th Annual Conference held 1930 in Washington, DC, President George Wallace called attention to the fact that the importance of institutional care should not be minimized because of increasing activity at the community level. In his view the institution side of the problem was "the rock and sheet anchor upon which large part of the work rests." He added that the more active community care became the greater would be the demand for institutional care. (Sloan & Stevens, 1976, p. 133)

In the course of the 1930 meeting, there was extensive discussion of sterilization and while no formal resolution was presented, there appeared to be a consensus that a program of selective sterilization was needed.

However, in the same year Herbert Hoover's White House Conference on Child Health and Protection, the third such conference since the first had been called by Theodore Roosevelt in 1909, issued a Children's Charter which was strongly oriented to community programs and in particular not only set forth every child's right to grow up in a family, but specifically also a mentally-handicapped child's right "to such measures as will early discover and diagnose his handicap, provide care and treatment and so train him that he may become an asset to society rather than a liability." (White House Conference, 1930) To be sure those were broad generalizations, but none the less important because they did not reflect the eugenic scare brought on at the turn of the century by the stories of the Kalikaks and the Jukes and still reflected in the title of a 1930 textbook by Stanley P. Davies Social Control of the Mentally Deficient. (Davies, 1930)

The major social product of the 1930's Franklin Delano Roosevelt's Social Security Act of 1935 contained no provision on behalf of persons with mental handicap. Indeed in many states, such children were specifically excluded either by law or by regulation from the benefits of the crippled children's provisions in title V of the Act. In other words, an IQ of 69 would be the reason for denying a child needed orthopedic surgery and it was not until the 1960's that this cruel practice was terminated.

At the 64th Annual Meeting in Atlantic City, AAMD President Frederick Kuhlman of Minnesota put forth what he saw as a long-overdue proposal: limiting the existing institutions to those who were capable to benefitting from training and establishing asylums for those needing custodial care. However, he also strongly supported development of the so-called colony plan, first established in Rome, New York, whereby the more capable institutional residents would be confined to small, segregated, rural housing complexes. (Sloan and Stevens, 1976 p.171)

While the presidential speeches of 1930 and 1940 were oriented along rather negative lines, emphasizing the role of segregated institutions, at the 65th Annual Meeting in Salt Lake City in 1941 Meta Anderson, Director of Special Education in Newark, New Jersey, presented a strikingly different picture. She did not just advocate strengthening special education programs in the community, she criticized the isolation of special classes from the regular educational life in the community. She stated: "It is not enough to enact laws compelling communities to establish special classes for the mentally handicapped. It is not only necessary but imperative that a program of living for the mentally retarded be established in school which will be so administered as to use all that is best in the education program for all the children." (Sloan & Stevens, 1976, p. 177) Furthermore, already in this 1941 address Meta Anderson reports on successful inclusion of mentally retarded children in some regular classes. While examples of anything resembling such inclusion were as yet hard to find, clearly, schooling was an area where steady progress was being made.

A paper by George Stevenson, Medical Director of the National Committee on Mental Hygene, presented at the 1947 Annual Meeting of AAMD entitled "Where and Whither in Mental Deficiency?" points to a negative development which is reflected in this field to the present days. (Stevenson 1947) The National Committee on Mental Hygene was founded in 1909 when Clifford Beers published his autobiographic book A Mind That Found Itself. But Clifford Beers was not just an author, I like to call him the first true self advocate in our history because he teamed up with a well-known psychiatrist Adolf Mayer to create a national mental hygiene movement with emphasis on prevention and early intervention in childhood. The National Committee's Division on Mental Deficiency laid the ground work for child guidance clinics which in the 1920's and 30's were a major resource to families of children with mental retardation. "Then dynamic psychiatry came along to give the coup de grace to the field of mental deficiency" wrote George Stevenson. He next pointed at the failure of social work practice and in particular social work training to confront the challenge posed by the 1% of the population recognized as mentally deficient. He said, "Many a social agency is relieved to get a diagnosis of mental deficiency in a troublesome case so that it can unload it on an institution (really on a waiting list where it is hopefully neglected)." He goes on to show that not just in social work, but in all other professions, including medicine and particularly psychiatry, there was a lack of even elementary training and interprofessionally a lack of coordination. I still remember Dr. Stevenson, a rather quiet, calm and thoughtful person and his strong across-the-board scathing critique was very disturbing to the leadership of AAMD.

At that time, a new challenge arose in the field: in various parts of the country, groups of parents of mentally retarded children were meeting, at first, informally and later organized as local associations. Some of these parents attended AAMD annual meetings in 1947 and '48 and indicated an interest in joining AAMD. In turn, some leaders of AAMD considered having these new parent groups join as an auxiliary group with some suggesting that the parents might help by raising funds for AAMD. Eventually, it developed that by the end of the 1940's more than 80 parent groups were part of some rather loose networks. Two of these groups had existed for a long time; one in Cleveland, Ohio since 1933, the other in the state of Washington since 1936, but they had been unaware of each other's existence proving once again that social innovations can exist in relative isolation over a long period of time.

In any case, the AAMD leadership extended an invitation to all known parent groups to come to the annual meeting held in 1949 in New Orleans. Mildred Thomson, a supervisor of community programs for mentally deficient in Minnesota's Department of Public Welfare, was chairman of the program committee and president-elect. She strongly rejected any notion of tying these new parent groups to AAMD and felt they should function independently of the professional group. (Thomson 1950) She had already been aware of the parent group in Minnesota and had worked with their leadership. Therefore, Ms. Thomson decided to title her presidential address at the 74th Annual Meeting in Columbus, Ohio "Together." She emphasized for all those within the Association to work together as well as to cooperate with the many national and international groups organized or exhibiting interest in the retarded, but especially with the parents. On the other hand, she felt that either group should be "free," able to act independently. Perhaps the most significant outcome of this Columbus Meeting was the decision by the parent groups to have a national convention later in the fall in Minneapolis. (Thomson, 1963)

Among the national groups to which Mildren Thomson referred was the National Mental Health Foundation. It had been created by conscientious objectors to military service who had been assigned in World War 2 by their draft boards to civilian service in state hospitals and in mental deficiency institutions. They were so appalled at the neglect and brutality they encountered that many of them resolved to work for institutional reform once they had finished their civilian service. Since they had had ample opportunity to recognize that poorly trained and poorly paid attendants were a major part of the pervasive institutional deficiencies. They published a journal entitled The Psychiatric Aide and a handbook for aides. (Sareyan, 1994) An interesting cross-connection to another pioneering reform group already mentioned is the fact that the selective service agency requested the National Committee on Mental Hygiene to assume supervision of the civilian work in mental hospitals and mental deficiency institutions. Both these organizations eventually ran into financial problems and in 1950 the National Committee on Mental Hygiene, the National Mental Health Foundation and the Psychiatric Foundation (organized by the American Psychiatric Association for fund raising purposes) merged to form the National Association for Mental Health. (Ridenour, 1966) As it turned out, NAMH did not become engaged with the field of mental retardation.

Another phenomenon, another "voice" originating in the 1940's needs to be mentioned here as another forerunner of the self-advocacy movement. It was in 1940 that Jacobus Ten Broek, a law school graduate who was not permitted to practice law due to his being blind, decided to form a new organization in the field of blindness then dominated by the National Foundation for the Blind. In stated opposition, he created the National Federation of the Blind, declaring the time has come for persons with blindness to speak for themselves, independent of charitable organizations. (Groce, 1992) The juxta position of the "of versus "for" has since gained international significance (there was a U.N. Year of Disabled Persons, not "for") and so I like to think of Jacobus Ten Broek as the second self-advocate in our country, Clifford Beers having been the first. (Matson, 1990)

In connection with the AAMD meeting in Columbus, five leaders of parent groups in Washington, California, Massachusetts, Ohio and New York drafted a two-page document entitled "Recommendation of the Steering Committee of Parents of Retarded Children Groups with Regard to the Formation of a National Organization of Such Groups." They called for an organizing convention of all groups to be held September 28 to October 1, 1950 in the Twin Cities, Minnesota. (Steering Committee, 1950)

The organizing convention was honored to have the Governor of Minnesota, Luther Youngdahl, as a featured speaker. What he had to say was indeed prophetic — he was at least two decades ahead of the times. Here are significant fragments of this address:

> "The point is this, ladies and gentlemen, the retarded child is a human being; above and beyond being a human being, he is a child and for reasons for which neither he nor his family are responsible, he is retarded. He has the same rights that children everywhere have. He has the same right to happiness, the same right to play, the right to companionship, the right to be respected, the right to develop to the fullest extent within his capacities, and the right to love and affection. He has these rights for one simple reason...he is a child and we cannot discriminate against this child, deny to this child the rights other children

> have because of the one thing that neither he nor his family can help, because he is retarded...he has a right to these things and his parents have a right to know that he has these rights. For they, too, are entitled to peace of mind about what is happening to a retarded child separated from them." (Youngdahl, 1950)

I was not privileged to attend that founding convention, as a matter of fact, I did not join the National Association for Retarded Children until January of 1957 but there is ample documentation of the wisdom and organizational skill of the association's founding fathers — and mothers. NARC started out as a grass roots organization with a deep commitment to the democratic process and the widest possible local autonomy. Other organizations such as the United Cerebral Palsy Associations of America have found it advantageous to have at least the presidency reserved for a prominent "name" person. In contrast, every NARC president has come up from the ranks and played a very active role. This was in part a consequence of the fact that for its first four years NARC had no staff, not even a headquarters office. Another important aspect of NARC s early history was a very comprehensive manual for the national board that set up procedures for association government, regulated intra-board relationships, contacts with press and government agencies down to such detail as a uniform filing system maintained by each board member.

Outreach was a major objective for the national board. Outreach within the board members' home territory, outreach to government and other organizations and from its early days, outreach internationally. When my wife and I visited Perth, Australia in 1968, professional workers there sang the praises of Dorothy Moss, who as chair of NARC's international relations committee had sent to Perth in answer to a request detailed information on a clinic for children with mental retardation, materials which helped Perth to organize its own venture. Mrs. Moss was bookkeeper for a small coal company in Cincinnati, but her outreach was worldwide. She was succeeded by other very competent chairpersons who continued this activity. Eventually the committee published an international newsletter which gained worldwide distribution and was credited by European parent leaders as having provided the base for initiating the International League of Societies for Persons with Mental Handicap.

Two books that played an important role in those early years in making the country aware of the problem encountered by families with retarded children were Pearl Buck's The Child Who Never Grew and Angel Unaware by Dale Evans. Dale Evans donated her royalties amounting to $10,000 to NARC and that made possible the opening of NARC's first headquarters in 1954. Through the cooperation of Mary Switzer, Director of the Office of Vocational Rehabilitation, Dr. Salvatore, DiMichael left OVR to become NARC's first executive director. Dr. DiMichael was thoroughly acquainted with the legislative process and the workings of the federal government and he prepared in January 1956 a masterful comprehensive document entitled Proposals on a Federal Program of Action in 1956 - 1957 for America's Mentally Retarded Children and Adults which was presented to Congressman John E. Fogarty, Chairman of the House Appropriations Sub-committee on Appropriations for the Departments of Health, Education and Welfare, and Labor. (DiMichael, 1956)

To make clear fully the significance of Dr. DiMichael's work, I first have to introduce Arthur Trudeau, a Rhode Island businessman and father of a son with mental retardation. It was Trudeau who persuaded his friend and former schoolmate, Representative Thomas E. Fogarty, to attend the 1954 Christmas Party of the Rhode Island Association for Retarded Children. Fogarty had become one of our country's leading health experts at that time — after all, part of his committee's work was to review requests for federal support from scientists, institutes, and the whole field of health, education and welfare. But nobody had ever appeared before his committee to talk about the problems the parents at the Christmas party were telling him, heartrendering accounts of lack of services, denial of services, isolation and segregation. Fogarty listened and promised help. And help he provided as he opened his annual subcommittee hearings on February 8, 1955 in Room F in the House of Representatives. The day started out in usual fashion with the Secretary of Health, Education and Welfare the Hon. Oveta Culp Hobby as the lead witness. They were discussing issues concerning programs for the aged when Fogarty switched the topic and said: "Now I'm going to go from the aging to the children. Some people call these children 'exceptional children' but they are generally referred to as mentally retarded. What are we doing on behalf of these millions of children in this country? This is the first year I have asked this question so it is something a little new I know." Secretary Hobby replied: "And I am not sure you are going to get a good answer."

Mr. Fogarty said that he himself knew little about the subject until he had attended a Christmas party last year, but now he would ask all those appearing before the committee what we are doing and what we can do about this problem. And so indeed he did. And the committee's proceedings available in print record those questions Fogarty addressed in subsequent hearings to the Surgeon General, to the Chief of the Children's Bureau, and to the Director of the National Institute of Mental Health.

Thus, thanks to Mr. Trudeau's inviting John E. Fogarty to a Christmas party, mental retardation, at long last, had gained due attention from the federal government in February of 1955. And Dr. DiMichael's comprehensive proposals provided Rep. Fogarty and his committee with the substantive data they would require in their deliberations. In the ensuing years, Mr. Fogarty continued to hear from NARC which on many occasions was most ably represented by Dr. Elizabeth Boggs, one of NARCs founders and now its one and only elder statesman (she would not want to be a statesperson).

In the early years of NARC, Dr. Boggs also served as chair of its education committee. We have come to think of educational change for children with mental retardation and other disabilities as having occurred in the '60's or '70's but the record shows some significant development in the '50's, such as the adoption of an Educational Bill of Rights for the Retarded Child presented by Dr. Boggs to the NARC Board of Directors, and adopted by the Board as the policy of the National Association for Retarded Children. (Proceedings 1953, p.30)

In 1953 the U.S. Office of Education published A Forward Look: The Severely Retarded Child Goes to School. In 1954 came the famous Brown vs. Board of Education decision of the Supreme Court which, of course, related directly to segregation of black children. But during arguments before the Court, John W. Davis, the attorney for South Carolina, appearing as friend of the Court, opened his argument as follows:

> "May it please the Court, I think if the appellants' construction of the 14th Amendment should prevail here, there is no doubt in my mind that it would catch the Indian within its grasp just as much as the Negro. If it should prevail, I am unable to see why a state would have any further right to segregate the pupils on the ground of sex or on the ground of age or on the ground of mental capacity." (Lippman and Goldberg, 1973, p. 13)

This was a prophetic statement indeed, but even though NARC's own newsletter reported it, nobody picked it up until another attorney, Thomas Gilhool, quoted it in 1969 in a case brought by the Pennsylvania ARC against state officials because of the exclusion of thousands of children from public school.

In the same year that the Supreme Court decided Brown, a conference sponsored by the U. S. Office of Education and chaired by Leonard Mayo issued a Creed for Exceptional Children strongly endorsing the right to education and nurture and ending with an affirmation of the rights of children with handicaps to a full life. (Mayo, 1954)

In 1957 the New York State Interdepartmental Health Resources Board published a major long-range study by Gerhard Saenger entitled The Adjustment of Severely Retarded Adults in the Community which reported surprisingly favorable results on the part of 520 former pupils of New York City's so-called low-IQ classes. (Saenger, 1959)

In the following year, the Journal of the National Education Association published a debate between Professor Cruickshank of Syracuse University and Professor Goldberg of Teachers College, Columbia University, titled The Trainables...Are They the Public School's Responsibilities? With Cruickshank saying no and Goldberg yes. (Cruickshank and Goldberg 1958) Dr. Goldberg's yes was reinforced the following year when the U. S. Office of Education published Education of the Severely Retarded Child: A Bibliographical Review. (Williams & Wallin, 1955)

Legislatively, two federal statutes contributed some measure of progress: in 1957 the Cooperative Educational Research Act and in 1959 P.L. 85-926 providing funds for training of professional educators for special education of mentally retarded pupils, two small, but trailblazing steps.

In 1953, NARC commissioned Dr. Grover Powers, Professor of Pediatrics at Yale, to chair its Scientific Research Advisory Board, which eventually hired Dr. Richard Masland to review the status of medical research in mental retardation. The results were published in 1958 under the title The Prevention of Mental Retardation — A Review of Research and this report was re-printed by Basic Books in 1959 as part 1 of the volume Mental Subnormality: Biological, Psychological and Cultural Factors, a major advance in a scientifically long-neglected field. (Masland et al, 1958)

To sum up the positive developments following the founding of NARC in 1950, Dr. Boggs wrote in October 1959 Decade of Decision — An Evaluation Report Prepared for the 1960 White House Conference on Children and Youth. (Boggs, 1959) And as if to echo her report, three leading popular journals, The Saturday Evening Post, The Ladies Home Journal and Look Magazine, all carried in 1959 major articles reporting on the progress in the field of mental retardation but depicting it as a childhood problem. (White, 1959; Brecher, 1959; Brossard, 1959)

As a consequence of the distinct advances made in the 50's, developments in the 60's not only accelerated but occurred simultaneously, making it difficult to present a reality picture.

Overall, the first half of the decade was dominated by the impact of President Kennedy's National Plan to Combat Mental Retardation, pronounced on October 11, 1961. (Kennedy, 1961) The President's panel he appointed prepared its comprehensive report in record time — less than a year — a most amazing achievement. (President's Panel, 1962) And, in addition, there were more detailed reports of task forces on various subjects and of missions to various countries. The President had decided on a committee of outstanding physicians, scientists, educators, lawyers, psychologists, social scientists and leaders in the field, but as the panel was assembled, many of its members had little prior contact with mental retardation as a societal phenomenon, and only a small minority of the panel remained visible and audible in our field after their assignment, the report, was finished. Dr. Elizabeth Boggs was the only person on the panel with significant ties to the parent movement and played an important role as vice chairman on the Task Force on Law to which reference will be made later. The most visible nationwide legacy of Kennedy's National Action is P.L. 88-164 creating the two national networks of research centers and of university-affiliated facilities, unfortunately of rather uneven quality and relevance to the challenges in the field. The Panel Report itself reflected the orientation of its membership by devoting only three out of 194 pages to a discussion of the family.

Another significant result of the Panel's work was P.L. 88-156 which, besides substantially improving maternal and child health services, set aside monies for each state to produce through the coordinated efforts of public and private agencies and with active participation of citizen groups a comprehensive mental retardation planning report. Every state complied and the sum total of these reports is an amazing nationwide accounting, but unfortunately I have found in my travels that in many states, top officials do not even know that these reports exist, yet they constitute for each state a most useful indicator whence we came. As not just a "by the way" let me remind you that similar reports were produced by each state by similar methodology with federal funds first in mental health and subsequently in vocational rehabilitation. Together these three reports present a unique panorama or, if you will, a telling benchmark where we were state by state in terms of human services in the mid 60's.

The term of the President's Panel expired with the submission of its report. Subsequently, President Kennedy appointed Dr. Stafford Warren of California as his Special Assistant on Mental Retardation and he in turn appointed a small group of consultants. I was among them, had a White House pass, ate lunch at the White House mess, but I can assure you I never got near a helicopter.

We were at a meeting to discuss implementation of P.L. 88-156 when the news reached us that the President had been killed in Dallas.

Dr. Warren eventually returned to California and there was an unfortunate and very noticeable void until President Johnson issued on March 11,1966 an executive order establishing the President's Committee on Mental Retardation which, as you may know, last year got revitalized with the appointment of Gary H. Blumenthal as Executive Director.

Another source of information of that period is the 1960 Golden Anniversary White House Conference on Children and Youth. Thanks largely to the presence of Dr. Elizabeth Boggs on the conference planning committee, there were several major presentations and discussion groups dealing with mental retardation. My assignment at that White House Conference was a report on "Trends and Issues in Mental Retardation" and a major point I made was the following:

> "Insufficient attention has been given in the past to the legal status of the mental retarded child and adult, particularly with reference to the degree of legal protection required as related to the degree of the mental handicap. A large number of retarded, by far the majority, are capable of moving about in the community, attending school, being employed or participating in formally organized or informal activities, yet by virtue of their being considered mentally retarded, are considered not to have the minimum endowment for an independent life. Conflicting views come into evidence concerning the ways in which the situation is being approached in various ways by our states. The existing sociolegal instrumentality of guardianship is a complicating factor since it does not allow for any limited personal guardianship but results in complete denial of independent legal status." (Dybwad, 1960a)

This challenge was taken up in 1962 by the <u>Report of the Task Force on Law, President's Panel on Mental Retardation</u> of which Judge David Bazalon was chairman and Dr. Elizabeth Boggs, vice chairman. (Bazelon et al, 1963) It is the one report emanating from the President's Panel which strongly and consistently speaks of the individual with mental retardation. It is this individual who is the focal point of the report which says, "one basic point is that all rights normally held by anyone are also held by the retarded." In 1962 that was indeed news.

Mention must be made here of the Civil Rights Act of 1964. While it did not mention mental retardation, in its strong, pervasive, national impact, it, of course, underlined and lent credence to the just-discussed developments.

In 1967, the International League of Societies for Persons with Mental Handicaps held in Stockholm, Sweden, a Symposium of Legislative Aspects of Mental Retardation. Dr. Elizabeth Boggs was the U.S. representative. In its conclusions, the symposium started a special section on individual rights with this introduction:

> The symposium considered that no examination of the legislative aspects of the problem of mental retardation would be complete without general consideration being given to the basic rights of the mentally retarded, not only from the standpoint of their collective rights and those of their families, but also from that . of the individual rights of the retarded person as a human being. (ILSMH, 1967)

There followed a detailed exemplified listing of general principles. When these conclusions of the Stockholm Symposium were presented to the League's Assembly held in 1968 in Jerusalem, the Assembly voted to have this section on individual rights rephrased and issued as a Declaration of General and Special Rights of the Mental Retarded. (ILSMH, 1968, p. 160)

The French member of the League persuaded its Ministry of Foreign Affairs to bring this Declaration to the attention of the United Nations and on December 20, 1971, against everybody's expectation, the United Nation's General Assembly adopted this document with a few editorial changes, the most significant being that the U.N. phrasing read "mentally retarded persons," not "the mentally retarded." (U.N., 1972)

You may wonder why I am using precious time to bring in this far-fetched story about the U.N. I did so because in his Order and Decree of April 13, 1972, Judge Frank H. Johnson of the United State District Court in Montgomery, Alabama, in re Wyatt vs. Stickney not only cited but quoted from the United Nations Declaration of the Rights of Mentally Retarded Persons to lend substance to his argument. (344 F.Supp. 387 [1972])

For the AAMD the 60's were a particularly productive period largely due to the leadership and sound judgment of Dr. Herschel Nisonger, who in 1960 became the Director of AAMD's Project in Technical Planning in Mental Retardation located in Columbus, Ohio, and supported from a major grant by the National Institute of Mental Health. The project's work concentrated on the production of program manuals, on the development of standards, and on so-called work conferences of senior professional staff.

After many years of fruitless discussions of international concerns, AAMD became in 1960 a co-convener of the London Conference for the Scientific Study of Mental Deficiency. Harvey A. Stevens had been the driving force in AAMD toward more international outreach and in London, he was commissioned to work on the draft of a constitution for an international scientific association, with a first meeting tentatively scheduled for Copenhagen, Denmark in

1964. With excellent cooperation from the Danish hosts, that 1964 conference was a most successful event and launched into being the International Association for the Scientific Study of Mental Deficiency. (Stevens, 1985) Earlier in 1960 several parent groups had established a European League which in 1961 expanded to an International League and eventually changed its name by using the phrase "for persons with mental handicaps." (R. Dybwad, 1967) By the way, the League is now in process of a further name change to move away from the term mental handicap altogether.

In the field of education, a major event was the enactment in 1965 of P.L. 89-10, The Elementary and Secondary Education Act which in Title I brought major benefits for children disadvantaged by poverty, disability or other reasons and who thus were for the first time included in general education legislation. P.L. 89-10 for the first time made federal dollars available to such children and it became the granddaddy of a long chain of statutes including P.L. 94-142, The Education of All Handicap Children Act, and P.L. 101-476, known as IDEA.

Unfortunately, the education practice in the various states was very slow to keep up with new and progressive legislation, and Pennsylvania was no exception. During those years, I had volunteered my services as a consultant to the Pennsylvania Association for Retarded Children and so it happened that on a weekend in the fall of 1968 a small delegation from that Association came to my office at Brandeis University to talk not just about the frustration in' trying to secure schools for their children, but also about the horrible inhumane conditions in their institutions. We once again reviewed the sad facts and all the various attempts the Association had made to bring about change and I finally suggested that since we had made over the past years repeated efforts to get help from the Secretary of Welfare and the Governor himself, as well as from the Secretary of Education, and since we had appeared before legislative committees with no results, there was a branch of government we had not as yet approached: the Judiciary — so why not petition the Courts for help. That made good sense to my colleagues and they went back to Pennsylvania quite happy with the prospect of this new approach. But when they had an opportunity to talk with the State Association's Board of Directors, their plan for court involvement was strongly rejected. Board members could not see how the Association could dare to sue the Secretary of Welfare when it had taken years to establish a personal relationship with her. And how could a lowly association think of filing a suit against the Secretary of Education. Over the next six months, the Board persisted in its viewpoint until the Chairman of the Institutions Committee at a Board Meeting decided to concentrate his report to the Board on just one incident leading to the death of a young child at a state institution. He included in his presentation a slide picture of the dead boy and hearing this boy's story and facing his picture on the large screen brought about a significant change: Board members realized that the amenity of a cordial relationship with the Secretary of Welfare had to take second place to the Board's crucial role to protect the interests, indeed the life, of children. (G. Dybwad, 1974) Permission was given to consult an attorney and explore possibilities of a law suit and Thomas Gilhool was entrusted with that task.

I have related this story here because in the course of my working in this field, I have found that all too often there is more concern with objective criteria such as the needs of programs, agencies and authorities, rather than with an individual's integrity, whether child or adult.

One paragraph of Mr. Gilhool's eventual report to the Board is worth noting here, since questions are often raised about court involvement.

> "There's nothing peculiar or extraordinary about litigation as a mode of social change. It is of the same cut as the other efforts of the Association to make use of other forums to define certain issues and to secure appropriate decisions by public officials. Litigation has inevitably not only the function of securing a particular result, but of displaying facts and conditions clearly and precisely both before the public and before decision makers, or redefining the questions that must be answered by both. There is and should be considerable interface between litigation and the other efforts of the Association." (Lippman and Goldberg, 1973, p.20)

Mr. Gilhool's suggestion to the Board was to initiate court action with regard to the problem of school exclusions rather than the institutional abuse and thus came about the PARC case about which we shall hear more presently.

Earlier I have made reference to P.L. 88-156 and the mental retardation planning projects funded by it in each state. In South Carolina the Executive Director of the Governor's Interagency Council for Mental Retardation Planning recognized the need for involving young people in the planning process. This resulted in the establishment of a youth task force which after an intensive training period held in several large cities meetings called "Youth Inquiry: Mental Retardation." In subsequent years, the work was extended on a regional basis. (Jaslow, 1967)

In 1965, the Division of Mental Retardation then located in the U.S. Public Health Service had budgeted monies to interest and train high school and college students in working with young people with mental retardation. In 1966, 700 students participated on programs in about 60 residential facilities, day centers, etc., and the programs was repeated in subsequent years.

In Texas, an organization named TARS (Texan Aid to Retarded) originated in 1965 in Dallas at the initiative of the executive of the Dallas ARC. It quickly became a state-wide organization committed to recruit teenagers to extend their friendship to children and youth with mental retardation. In 1967 the National ARC organized "Youth NARC" and I have in my files the program of a four-day conference "Accent Youth" in Detroit which is described as the second annual youth conference on mental retardation. In 1969, NARC published a Youth NARC Orientation Handbook and an Organizing Manual. (NARC, 1969 a and b)

It is interesting to note that as far as I can determine, all these projects have disappeared, but I hope that someday somebody will try to explore to what extent these youth activities played a preliminary role in the early beginnings of self-advocacy in our field.

The decade of the 1970's was most exciting and most rewarding for me as a committed person in this field. It began with a startling change of pace: the introduction of the Developmental Disabilities Act of 1970, P.L. 91-517. Again, Elizabeth Boggs was at the cutting edge of change. She and a friend and colleague, Dr. Elsie Helsel of the United Cerebral Palsy Associations, had observed how the pace of funding and programming had slackened in the late 60's and decided a new approach was needed which looked at the field in more comprehensive terms. They worked hard to secure congressional support and succeeded admirably. (Boggs, 1972) One of the remarkable features of the developmental disability legislation was that the statute introduced a concept and terminology new to academia and practice alike, in contrast to the more usual occurrence that new concepts are long discussed, written about and researched before legislation develops. From the beginning the DD legislation was upbeat and not just consumer-friendly, but consumer involved. Nobody recognized this more clearly than Senator Javits of New York, who, dying with cancer, fought valiantly to have added to the 1975 DD Amendment P.L. 94-103, a Bill of Rights, underlining the new thrust of this federal legislation. Overall the Protection and Advocacy feature of the DD legislation was a very potent addition even though its quality differed markedly from state to state.

The 1978 amendments to the DD Act P.L. 95-602 included a radically-changed definition shifting it from the traditional categories to a functional approach and adding an emphasis on the more severely involved individuals.

In vocational rehabilitation, PL 93-112 brought in 1973 a priority in favor of more severely disabled persons, surely one of the most consistently ignored statutory provisions. In contrast Section 503 and 504 of the Act dealing somewhat extraneously with human rights, have played a very important role across the human services.

In 1975 Congress passed PL 94-142, The Education of All Handicapped Children Act, a mighty step forward toward school integration even though in actual practice the "all" carried with it a few grains of salt. Still, all in all, the legislative progress was impressive, but it was matched by a new phenomenon in the human services field — a steadily growing number of judicial actions on behalf of persons with mental retardation, both in the community and in institutions. The first case was the one filed by the Pennsylvania Association for Retarded Children against Pennsylvania state agencies. After listening to one day of testimony by PARC's expert witnesses, the three-judge Federal District Court suggested that since the State had not contested the major portions of the plaintiffs' claims to wit that no child should be deemed ineducable and thus excluded from schooling, the parties should work out a consent agreement. This was done and in due time, the Court approved it.

Shortly after the PARC case had been started, a class action suit Mills vs. Board of Education was filed in Washington, DC, and in that case, the plaintiffs represented not just children with mental retardation but with a cross-section of disabilities. This case ended in a judgment by the U.S. District Court which makes for very interesting reading. In response to the District's claim they needed additional funds before they could admit children excluded on account of disability. Judge Waddy stated:

> "The District of Columbia's interest in educating the excluded children clearly must outweigh its interest in preserving its financial resources. If sufficient funds are not available to finance all of the services and programs that are needed and desirable in the system then the available funds must be expended equitably in such a manner that no child is entirely excluded from a publicly supported education consistent with his needs and ability to benefit therefrom. The inadequacies of the District of Columbia Public School System whether occasioned by insufficient funding or administrative inefficiency, certainly cannot be permitted to bear more heavily on the 'exceptional' or handicapped child than on the normal child." Mills v. Board of Education (1972)

The first of the institutional class action suits was Wyatt vs. Stickney, relating to the Partlow State School and Hospital in Alabama before Federal District Judge Frank M. Johnson, Jr. whose citing of the U.N. Declaration of the Rights of Mentally Retarded Persons I have mentioned earlier. (Wyatt v. Stickney, 1972) Attending his courtroom was a great experience, the very pronounced decorum of the Court and the quiet, calm voice of the judge were in such paradoxical contrast to the unending stories of unspeakable brutality, stench and filth, human depravity and lack of even minimal sanitation which witness after witness outlined in gory detail. For me, attending as an expert witness, Judge Johnson's courtroom was one of the unforgettable experiences in my life. Over the next years I was requested to testify in some fifteen other institutional court cases throughout the United States and it was depressing to hear year after year about the same violations of human rights, the same neglect, the same gross violations of human decency, and, alas, the same tolerance of the institutional neglect and brutality by professional staffs. We cannot, we must not overlook the indisputable fact that in all those abominable institutions, there were physicians, psychologists, psychiatrists, social workers and various therapists as well as educators, most of whom were members of professional associations which were committed to codes of ethics. Yet, until the law suits were initiated by outsiders, there had been no protest brought forward by any of the professional associations.

Another aspect of ethical considerations was brought to the fore by the Kennedy Foundation in October of 1971 through the showing of the film Who Shall Survive? It depicted an actual occurrence at Johns Hopkins Hospital in Baltimore. A woman had given birth to a baby with Down syndrome who needed immediate, but relatively minor, surgery for an intestinal obstruction. The parents refused to give permission of the surgery. The baby was removed from the nursery to a side room and died two weeks later having been starved to death. (Rothman, 1991) Even though the Kennedy film and the proceedings of a conference discussing it, were given wide publicity, the country in general, and the relevant professional groups in particular, were ill-prepared when ten years later the death of Baby Doe, another infant with Down syndrome caused a heated nationwide public debate.

Another significant development in the 1970's was the beginning of The People First Movement. About twenty-five years after the first parent groups developed in the 1940's, groups of what became known as self-advocates appeared in this country. To Oregon and Washington must go the credit as the original pioneers, but the movements spread quickly and gained from close contacts with Canadian groups. The name People First emanated from this interaction.

There is no doubt that the initiative for this movement came from Sweden where Bengt Nirje, well known for his pioneering writing on the normalization principle, had discovered as ombudsman for the Swedish Parents Association that groups of young people in the Association's recreation program were far more capable of selecting and planning their activities than had seemed possible. At his suggestion, the Board allocated funds for some training sessions so as to enable these young people to take a more active part in programs which previously had been selected for them and to help them toward more skill in decision making. After Nirje had presented his experience with those pioneering Swedish self-advocates at a Congress in Dublin, Ireland, his ideas were rather quickly picked up in England, Canada and the United States. (Nirje, 1971) Already 1973, a state ARC received a foundation grant supporting a project involving self advocates. Conferences of self advocates were beginning to be noted in the press and a slogan such as "Yes, we can" created a favorable climate.

In 1978 my wife was involved in planning the International League's Seventh World Congress in Vienna and in conversation with others, the idea came up to have some self advocates present and participate in that Congress. Dr. Clarence York of the Bancroft School and Community became interested and managed to arrange for a small group to travel to Vienna. At that time this seemed to be a formidable undertaking (an indication of our timidity) but all went well. There was a moment when we agonized in what special ways we should recognize at the Congress the presence of these young people but then the point was made, nobody else was recognized by the Congress in a special way so happily the idea was dropped. They came as regular Congress participants and were received as such.

Everything worked out so well that plans for the 1982 Congress of the International League which took place in Nairobi, Kenya included from the beginning plans for strong presence of an international group of self advocates. Delegations from eight countries were present and with the help of volunteer interpreters, the group of some forty self-advocates developed in remarkedly short time a sense of cohesion and team spirit.

One of their main tasks was to prepare for the fourth day of the Congress a plenary session to present their own ideas and feelings. And this they did, having selected eight from their midst to speak for them. An international audience of 700 people representing sixty-five countries listened and in the second half of the session had an opportunity to engage the eight self advocates for an unrehearsed discussion.

For most of the audience, it was a startling revelation to see and hear people considered incompetent to speak so well for themselves and respond to challenging questions, at times with a good sense of humor.

At the League's next Congresses in 1986 in Rio de Janeiro and in 1990 in Paris, there was an ever-increasing participation of self advocates and some of them by this time were quite critical of what they saw as inadequate consideration of their needs as Congress participants.

Meanwhile, the people-first movement had their own International Congresses in 1984 in Washington State, in 1989 in London, England, and in 1993 in Toronto, Canada, quite a remarkable achievement considering how long it took AAMR to move into the international field.

The Toronto Congress was for me a very moving experience beginning with an evening opening session with a long procession of the flags of the more than thirty participating countries. During the Congress, most speakers and most moderators came from the People First ranks and sessions were organized to allow a maximum of participation. Keynote speeches each morning were limited to ten minutes, something AAMR might well consider to adopt for its own meetings where often, after forty-five minutes of listening, you wonder what the keynote really was. For those not yet used to large conference meetings, there were in Toronto many small discussion groups, limited in size and with no "outsiders" present.

But most impressive for an old-timer like me was the sight of a large hotel ballroom with more than 1,000 conference participants seated at dinner tables quietly having a meal. Of course, the proper comment is "and why not?" But that is precisely why I began my presentation with the grim and, in retrospect, most painfully embarrassing realities of past decades.

Forty-five years ago, Mildred Thompson as AAMD President concluded that it would not be desirable, as had been suggested, to have the newly organized parent groups join AAMD under whatever arrangements. I am sure if Mildred Thompson could be here today, she would be pleased to observe that among the participants at this conference are a considerable number of self-advocates, not only speaking for themselves, but representing their own national organization, duly incorporated, and recognized as a non-profit voluntary association about to have its first convention under its new name Self Advocates Becoming Empowered.

My purpose for this presentation was to highlight the importance of this new organization, the wisdom and dedication of its leadership, and its potential contribution towards changing traditional patterns in the community. It is for that reason that I started out with the dark days of the 30's and 40's, when the most basic human rights were denied to those who now rightly claim to have achieved not just personal but also organizational independence.

So allow me a somewhat unusual but well reasoned request: please join me in applauding the leadership and members of Self Advocates Becoming Empowered.

Good luck to you Nancy and Roland, and T. J. and all the others. You have come a long way. but there is quite a journey still ahead of you.

As for the rest of us, there lies a tough task ahead because, let us be honest, we are not as ready to face the challenge brought to us by the self-advocacy movement as our policy statement on Self Determinination may suggest. Innumerable obstacles are in the way - job descriptions, regulations, even the very words we are using, administrative routines, legalistic reasoning, and, yes, liability and other administrative safeguards - they all are apt to interfere with our good intentions. But as always, I am an optimist. I rejoice how far we have been allowed to travel, and I have no doubt that the journey will go on.

References

Bazelon D., Boggs E., Hillebee, M., Tudor, W. (1963). Report of the Task Force on Law, The President's Panel on Mental Retardation. Washington, D.C., U.S. Public Health Service.

Boggs, E. **(1959).** Decade of Decision. An Evaluation Report for the 1960 White House Conference on Children and Youth. New York, National Association for Retarded Children.

Boggs, **E. (1972).** Federal Legislation 1966-1971 in J. Worthis Mental Retardation Volume IV. New York, Gruen and Stratton.

Brecher, R. & Brecher, E. **(1959).** Saving Children from Mental Retardation. Saturday Evening Post, November 1959.

Brossard, C. (1959). Mentally Retarded Children - They can be helpful. Look, November 24, 1959.

Buck, P. (1950). The Child Who Never Grew, New York, John Day Co.

Cruickshank W. & Goldberg, I. (1958). The Trainables...Are they the Public Schools' Responsibility? NEA Journal, December 1958.

Davies S. (1930). Social Control of the Mentally Deficient. New York, Crowell.

DiMichael, S. (1956). Proposals on a Federal Program of Action in 1956-57 for America's Mentally Retarded Children and Adults. 50 pg. mimeo. New York, National Association for Retarded Children.

Dybwad, G. (1941). The Problem of Institutional Placement for High-Grade Mentally Defective Delinquents. American Journal of Mental Deficiency, Vol XLV. No. 3.

Dybwad, G. (1960). Trends and Issues in Mental Retardation. In: Children and Youth in the 1960's. Washington, D.C. Golden Anniversary White House Conference on Children and Youth.

Dybwad, G. (1974). The judiciary's protective role and the separation of powers in the light of recent consumer-inspired court cases. Proceedings of the 15th Anniversary Symposium on Social Policy. Waltham, Heller School, Brandeis University.

Dybwad, R. (1967). New Developments in International Organizations in the field of mental retardation. International Social Work **10,4.**

Evans, D. (1953). Angel Unaware. New York, Revell.

Groce, N. (1992). *The U.S. Role on International Disability Activities*. Berkeley, CA. World Rehabilitation Fund.

ILSMH (1967). *Legislative Aspects on Mental Retardation. Conclusions, Stockholm Symposium.* Brussels, International League of Societies for the Mentally Handicapped.

ILSMH (1968). *From Charity to Rights. Proceedings 4th International Congress,* Brussels, International League of Societies for the Mentally Handicapped.

Jaslow, R. (1967). *We Are Concerned. Three Youth Programs for the Mentally Retarded.* Washington, DC, Division of Mental Retardation, H.E.W.

Kennedy, J. F. (1961). *A National Plan to Combat Mental Retardation.* Reprinted in President's Panel Report (listed below).

Lippman L. and Goldberg, I (1973). *Right to Education. Anatomy of the Pennsylvania Case and its implications for Exceptional Children*. New York, Teacher's College Press. " -

Masland, R., Sarason S., **Gladwin** T. (1958). *Mental Subnormality.* New York, Basic Books.

Matson, F. (1990). *Walking Alone and Marching Together: A History of the Organized Blind Movement.* Washington, D.C., National Federation of the Blind.

Mayo, L. (1954). *Creed for Exceptional Children,* U. S. Office of Education Conference • on Qualification and Preparation of Teachers of Exceptional Children.

Mills v. Board of Education. United States District Court, District of Columbia 348 F. Supp. 866 (1972).

NARC (1969a). *Youth NARC Orientation Handbook.* New York, National Association for Retarded Children.

NARC (1969b). *Organizing Manual for Youth Organized and United to help NARC.* New York, National Association for Retarded Children.

Nirje B. (1971). Toward Independence. *Mental Retardation.* (Canada) 21, 2.

President's Panel (1962). *A Proposed Plan for National Action to Combat Mental Retardation.* Washington, D.C., President's Panel on Mental Retardation.

Ridenour (1966). *Mental Health in the United States*. Cambridge, MA, Harvard University Press.

Rothman, D. Strangers at the Bedside. New York, Basic Books.

Saenger, G. (1959). The adjustment of Severely Retarded Adults in the Community. Albany, NY, NYS Interdepartmental Health Resources Board.

Sloan, S. **and** Stevens, K. (1976). A Century of Concern. A History of the American Association on Mental Deficiency. 1876 - 1976. Washington, D.C. American Association on Mental Deficiency.

Smith, B.K. (1968). Boomerang Friendships - A Story of the TARS. Austin, TX. Texas Aid to the Retarded.

Steering Committee (1950). Recommendations of the Steering Committee of Parents of Retarded Children Groups with regard to the Formation of a National Organization of such groups. 2 pages mimeo.

Stevens, H. (1985). American Association on Mental Deficiency: Participation in International Activities. Mental Retardation 23, 5:215-218.

Stevenson, G. **(1947).** Where and Whither in Mental Deficiency. American Journal of Mental Deficiency 52:43-47.

Thomson, M. (1950).Together. American Journal of Mental Deficiency 55: 2-13.

Thomson, M (1963). Prologue - A Minnesota Story of Mental Retardation. Minneapolis, MN, Gilbert Publishing Co.

United Nations (1972). United Nations General Assembly Declaration on the Rights of Mentally Retarded Persons. A/RES/2856 (XXVI) 21 January 1972.

Wyatt v. Stickney (1972). 344 F.Supp. 387 (MD Alabama, 1972).

White, G. (1953). Children of the Dark. Ladies Home Journal 76:164.

White House Conference (1930). Children's Charter. Reprinted in Child Health USA '91. Washington, D.C. U.S. Public Health Service (DHHS Pub. No. HRS -M-CH **91-1).**

Williams H. and Wallin, J. E. (1959). Education of the Severely Retarded: A Bibliographical Review. Washington, DC, U. S. Office of Education.

Youngdahl, L. (1950). Address to the Founding Convention of the National Association of Persons and Friends of Mentally Retarded Children, (mimeo)