

END NOTES

1- Inclusion refers to an educational model for children with disabilities that emphasizes their full participation in same chronological age classrooms whatever the child with disabilities' academic level. This model is distinct from mainstreaming, in which children with disabilities participate in separate classroom in a school but join regular classes in those subjects in which they are on grade level.

2- The article titled "**Not Like OTHER Children**" is remarkable in several respects. First, that the mother wanted to remain anonymous, and yet the article is simply a beautiful exposition of her and her husbands efforts to educate their "feeble-minded" son. Yet her shame was so great that she would not sign her name to the piece. Even more stunning and indicative of the thinking of that time was her conclusion. After telling about all the hardships and efforts they made to physically and mentally stimulate their son she writes, "We know that the hardest part of all is yet to come. For if we ever have other children, we must make provisions to have our 'different' little boy live away from home. It is too bitterly unfair to let a normal child face the pity, the curiosity, the whisperings about a defective child that we, as adults, find it hard to meet. Then too we know that our handicapped child would be miserable if he had to compete, though it might only be in the playground, with normal children. He has the right to be among his own kind, where he need face no unfair competition. Only so can he possibly be happy as he grows older. Anyone who doubts this need only think back to his own childhood, to remember with shame how heartlessly the neighborhood idiot was teased. Those are plain words but this is a situation that calls for plain thinking...We may gloss over the facts but the world won't. The time will come when it will be best for our child to go to a special institution." The mother then goes on to lament how her son will always be in their hearts and minds, even though they will not be able to help him any further. It is quite striking to me that a parent such as the one that wrote this article, who was clearly

devoted to helping her son, was so universally surrounded by such negative attitudes that she herself had come to accept them as natural. The article illustrates how deep the stigma and shame of retarded children was during this time in history, and how it was an inescapable fact of life for even the most devoted of parents.

3 - I take this remark to refer to Ann's eventual understanding that all parents of children with mental retardation share certain common experiences, whatever their decisions about the welfare of their family.

4 - The role of chance in the development of the parents' movement and mental retardation should not be underestimated. Gunnar Dybwad, Executive Director of the National Association of Retarded Children in the 50's and 60's tells the following story about the mental retardation movement on the Federal level. A similar event occurred in 1955, when Arthur Trudeau, wealthy businessman and parent of a child with mental retardation, happened to meet John Fogarty who was then head of the House Sub-Committee on Appropriations for Health and Human Services (making him one of the most powerful persons in this country with regard to children services). It happened that Trudeau knew Fogarty through his lobbying activities in Washington, and it happened that one Christmas evening in 1955, Trudeau was to bump into Fogarty as he was leaving work and invite him to a Christmas party. It was there that Fogarty was exposed to the plight of children with mental retardation and their families. In the next meeting of his sub-Committee he pushed hard for legislation on the federal level, and suggested the formation of a Congressional panel of experts on the topic, a precursor to the President's Panel that was to be created by President Kennedy in 1961. The Conklin-Weingold meeting and the Fogarty-Trudeau encounter both show how chance played a significant role in the development of the field.

5- The source for this document were the personal files of Gunnar Dybwad, housed

in the Howe Library on the grounds of the Fernald School. The draft document appears in published form the next year in the American Journal on Mental Deficiency, Vol. 45: 326-328. The following briefly characterizes its provisions. Under "Institutional Care" there is a discussion of the extent, nature, administration of, specialized services in, and special study and control of state schools and hospitals. Mentioned under the heading "State Extra-institutional Care" is the need for intermediate care in addition to 'parole service' (ie, being released from an institution and under social supervision) such as hostels, family care, supervised clubs, standards for personnel (interestingly citing standards developed by the New York City Committee for Mental Hygiene) and the need to develop better relationships with organized labor to "effect vocational adjustment." Under the topic heading, "Education in Public Schools" there are recommendations with respect to extent ("ungraded or special classes" to meet the needs of about 1% of the school population), nature (programs should be set up to the capacities of each child and include social and occupational training), and after care (ie, the need for social services and vocational teachers to help youngsters find and keep employment). Under "Research" the document calls for broad research into the incidence, causes, treatment and social planning in each state. Then under "Coordination of Work" the document presents what is essentially a call for statewide planning that would coordinate all the state agencies necessary to address the problem of "defective adults and children." Finally, the document calls for, under the heading "Educational Work," education for professional groups (including institution staff, doctors, psychologists, clergy, teachers, social workers, nurses and staff of welfare agencies) and lay groups (including parents and foster-parents, the general public with regard to attitudes and making a "proper provision" and public officials as to the need for public expenditures.

6- This early participation of parents in the deliberations of AAMD on nomenclature change was substantiated in part by the personal files of Elizabeth Boggs housed at

the Howe Library. The particular document mentioned is a blue mimeo sheet (1952) of the Nomenclature Committee, on which Elizabeth sat as an ex-officio member. She actually was a member of AAMD, having received membership, in her words, "before they kicked the parents out."

7- Mr. Harvey Pacht, of the Self-Advocacy Organization of New York State put these feelings into words very well, "Mental r, [he will not actually say the words 'mental retardation'- DG] we don't like those words. They were misused and misinterpreted by a lot of people. Especially children on the streets...Those words were used to dehumanize people and hurt them...People with disabilities cannot and never will be comfortable with those words...always associated with horrible things they remember in the past...It is like a cloth with a bad stain. No matter how many times you wash it, the stain will never come out."

8- In 1957 Alfred Katz received a Ph.D. degree from the New York School of Social Work with a dissertation titled, "An Investigation of Self-organized Groups of Parents and Relatives in the fields of Physical and Mental Handicap." This document is the source of this data.

9- Jerry Lewis' MS telethons are another example, although his portrayal of 'spastic' characters in the movies of this era had many parents of children with disabilities up in arms. Also, Danny Kaye's portrayal of a parent of a child with polio in the 1950's movie "The Five Pennies" is another example of the growth of media awareness of disability issues in the 1950's. In 1961, an episode of the television show "The Defenders" was devoted to the issue of physician euthanasia of a "Mongoloid" child.

10- It is interesting how a simple phrase such as 'pilot classes begun in 1951' can mask the human story to which it points. Devino Riandoto, an Italian immigrant

without specific education in mental retardation, was the first teacher hired by AHRC and one of the interviewees for this project. Riandoto was actually hired in 1953 as the first full time AHRC staff teacher, and began teaching in the basement of a Jewish Synagogue in Brooklyn. He had eleven boys and twenty girls in his classroom, with no assistants. He remembered how parents had access to the class and that they were really his bosses. He 'learned on the job,' and given the nature of his job, a single teacher in a classroom of 31 'trainable' mentally retarded children, he quickly learned many lessons from his children. Riandoto recounted the pride with which he regarded his own work, in the face often of public ridicule ("And I stood it...in the school as well as on the street...I was proud...I walked straight up...I felt second to none.") He dealt with difficult behaviors ("As for difficult behaviors we had them...name it...You had to have a gold heart and a steel frame. A gold heart to feel that they are part of you. To a point strong to be able to cope physically...in a tantrum...you see these desks fly by..."). He described being a teacher to these children as requiring him to be "a man for all seasons," doing whatever it took to get the job done. He recalled the practical nature of much of his teaching, exposing his children to normal experiences, like shopping or going to Chinatown, or teaching them how to interact with one another. Riandoto described how he and his children built a strong respect and love for one another, how his last classes recently gave him a reunion, and I could feel how important that was to him. He never married or had children and to him his students are his children. Hearing him speak of his students one could feel his attachment to them. But hearing Devino describe his early experiences, to hear what it was like in those first classrooms, was overwhelming. I kept imagining to myself what it must have been to be alone in a classroom of 31 children with severe mental retardation, most of whom had never been to school before, with no training, and no one to help. No wonder he needed "a heart of gold and a steel frame." It is through people like Devino Riandoto that the educational aims of AHRC were given real form and reality. It is the everyday world that Riandoto and his students created in these classes that is the true story of

AHRC's early experiments in classroom education for trainable children.

11- In Elizabeth Boggs' files related to NARC, there is an entire folder devoted to "the New York Question" in which are found thirty letters (end of the 1950's) to and from NARC to AHRC and to The Welfare League and other institution groups, about various matters, but especially who should be the State's member to the NARC. There was bad blood in the air about this situation, and funding issues related to it.

12- The conflict between AHRC and the NARC, and then later the NYSARC and NARC, was due to many factors. Strong personality conflicts, perceived anti-Semitism, substantive differences on issues (for example, on the questions of whether ARCs should go into the provider business, and the role of workshops in the lives of people with mental retardation). In an interview with Gunnar Dybwad, Executive Director of NARC during the late 1950's and 1960's, he remembered well the tension at national meetings between NARC, AHRC and other parent groups. He remembers the perception of the group as being "the Jews from New York City" and that Weingold was particularly argumentative and insistent that things be done his way. Dybwad, now 89, felt that Weingold resented Dybwad's appointment as Executive Director, and believed that he (Weingold) should have received that position. Whatever the actual case, one can feel the conflicts between AHRC and NARC had many levels to them.

13- The term 'developmental disabilities' began to be employed in the early 1970's and entered federal legislation in 1975. It is a legislative term, not a scientific or clinical one, and was invented to control entitlement to persons with disabilities. It is a functional definition of disability designed to ensure that only those with severe and (possibly) life-long disabilities get access to the most desirable funding streams.

14- In fact, exposés of conditions at New York state hospitals and schools, and investigations of 'incidents' within them have been part of newspaper coverage throughout this century.

15- As of this writing Ira Wohl's twenty year update of "Best Boy," called "Best Man," is awaiting release on Cinemax. This project was again done with the cooperation of AHRC and involving AHRC programs and staff.

16- The fact that Stone began to sensitize the agency to issues of accessibility so early on in the development of residential services created a tremendous number of beds within the agency that were located in wheelchair accessible residences. Gerry Maurer commented that AHRC probably has more accessible beds than any other New York City agency other than United Cerebral Palsy, which specializes in persons with physical disabilities. This great number of accessible beds presents unique opportunities to the agency at the time of this writing. Specifically, it allows AHRC to permit their residents to "age in place," as Gerry Maurer put it. This means that AHRC can provide home care services to persons in fully accessible environments who would otherwise face placement in a nursing home.

17- Today there are several national coalitions for the training of workers in mental retardation, one of which is sponsored by the Kennedy Foundation, the President's Committee on Mental Retardation and in cooperation with the American Association on Mental Retardation. Since the inception of the Goldfarb/Gorelick idea, the City University has also engaged in policy development, research and international exchange and development in the areas of worker training.

18- Goldfarb expressed a deep ambivalence about the current ideologies in services for persons with mental retardation. While acknowledging that some changes have been extremely beneficial (for example, the move away from

institutions toward choice-driven support systems) others have been very negative. In fact, he felt that "...the origins of the current ideology are essentially a fabric of concepts and points of view not very much driven by empirical information, in which the mistrust of pre-existing service systems [such as AHRC] is the driving force, the vector." Further, the down side of the philosophies is that "a lot of the States have simply defended those programs because it became academically fashionable to do it. States closed their workshops and did not replace them with substantial or suitable alternatives." Thus, Goldfarb's argument with the academic ideologists in the field is not just a philosophical one, and his differences with their positions are not simply a matter of theory.

19- Thus Goldfarb remarked that in some ways the administration of AHRC today is as, or in some cases is even more, conservative than the Board. He cited the recent suggestion by the Board to Judy Delasi that she shorten the incident review process that the agency employ and that she herself need not review in detail each case. She rejected the Board's advice.