

YOUNG ADULT INSTITUTE & WORKSHOP, INC.



From the 60s into the 80s: An International Assessment of Attitudes and Services for the Developmentally Disabled



Papers from a conference organized by the Young Adult Institute & Workshop, Inc. in support of the International Year of Disabled Persons

April 6-10, 1981

Editors: Joel M. Levy, Philip H. Levy, Nina Liebman, Thomas A. Dem,

Rosamond Rae, Thomas-Robert Ames

Forewords by: Niels Erik Bank-Mikkelsen, Bengt Nirje

Introductions by: Thomas-Robert Ames, Gunnar Dybwad, Margaret J. Giannini,

James E. Introne, Hugh G. Lafave, Joel M. Levy, Harold Michal-

Smith, Martin B. Miller

Afterword by: Burton Blatt

Contributors: Alfred A. Baumeister, Elizabeth M. Boggs, Herbert J. Cohen,

Allen C. Crocker, Reuven Feuerstein, Stanley S. Herr,

Kazuo Nihira, Zygmond L. Slezak, H. Rutherford Turnbull III, et al.

From the 60s into the 80s: An International Assessment of Attitudes and Services for the Developmentally Disabled

Editors:

Joe! M. Levy
Executive Director
Young Adult Institute & Workshop, Inc.

Philip H. Levy
Associate Executive Director
Young Adult Institute & Workshop, Inc.

Nina Liebman
Coordinator of Public Information and Special Events
Young Adult Institute & Workshop, Inc.

Thomas A. DemDirector of Community Education Young Adult Institute & Workshop, Inc.

Rosamond Rae Senior Psychologist Young Adult Institute & Workshop, Inc.

Thomas-Robert Ames
Assistant Professor of Community Mental Health
Department of Allied Sciences
Manhattan Community College, City of New York

Associate Editors:

Patricia A. Witterschein Assistant, Public Information Department Young Adult Institute & Workshop, Inc.

Celia A. Hartmann Consultant

The development of this publication was made possible through a grant from the New York State Office of Mental Retardation and Developmental Disabilities, in conjunction with the New York State Advisory Council on Mental Retardation and Developmental Disabilities, through the federal Developmental Disabilities Assistance and Bill of Rights Act as amended by P.L. 95-602.

Closing Session: Formula for the 80s

Professionals and consumers discuss programmatic needs of the 80s as an outgrowth of their personal and professional experience in the 60s and 70s.

Hugh Lafave: I do not have a formula for the 80s. In the 60s I had a formula. A bunch of professionals got together and devised something and it did not work. In the 70s we got a little more complicated. We worked with consumers to develop a formula and we got ourselves so bogged down in services that when politicians changed and bureaucrats changed, we watched 10 years of work swept aside and replaced. I do, however have a hope—! am an eternal optimist—that out of their sense of courage, outrage that I see growing in leaps and bounds, and out of their sense of hope, consumers will be heard when they say what they mean. If they can not—if the person lives with a disability and can not—that their families and their friends advocate and make rights the issue now, and unite and ally in an issue-oriented way to see that what should happen does. I begin the panel on what I hope is not too sour a note and I hope that I do not see formulas that are pat and that will not work. I see a lot of painful, trying, and difficult times and if they have any good to them, we will see the consumers in a movement that really makes a difference.

Bengt Nirje: I would like to provide some ideas about the developments in Sweden and where they are heading in the 80s. To do so, I quickly have to take away some of the myths about institutions. Frankly, we really do not have any, in the same sense as the image of the American institutions. The background is simple because we were decentralized 100 years ago, with regional governments, 25 of them, given responsibility for health services and later for services for the mentally handicapped. There were institutions in the 50s and certainly in the 60s and they were too large—sometimes 300 to 500 people. One part of the development in Sweden in the 40s, 50s, and 60s was to establish new living standards in the residential homes for the mentally handicapped. Today there are 171 residential homes: 47 for children and 124 for adults. The average has been roughly 30 for children and 60 for adults. Of those persons, 8,000 are severely retarded, and more than 50% of them are over 40 years of age. In the smaller homes, 50% have been in single rooms and 40% have shared a room. In 1970 5 persons might have been sharing one room but that doesn't happen any longer.

What we did in the 60s and 70s was to develop more community services and integration when it comes to the schools; we have compulsory education for all children. All children are individually integrated, in preschool from the age of 5, and all children go to classes that are physically integrated in regular school sectors. The tendency is now to transfer the school system, with its services for the mentally handicapped, into the regular community school system. That will be the proposal of a current parliamentary committee. Services for mentally handicapped will be extended to other handicaps that do not have the benefits of the developments here. So some other handicaps will have the same type of services included in the social care for children. When it comes to adults, development has been towards more accommodation services and independent training programs in the community. The tendency in the 80s will be towards total integration of services for children in the educational system and the social service system, to coordinate the child's education with programs. For the adults, it will be an increased development of accommodation living.

When I left a few weeks ago, I was dealing with and planning my budget for 1986 for the new programs. We have 5-year plans. Next year we are developing the plan for 1983-1987. The pressure is not that great for deinstitutionalization because we do not have institutionalization. In those residential homes, the pressure to move out into the community is not that strong. There is quite a cultural difference there. More and more severely handicapped persons go from school programs into community living.

The other item that certainly would be a sign of the 80s is the voice of the handicapped persons themselves. All the planning of the parliamentary committee has certainly included handicapped people giving their opinion. Due to the Swedish accomodations since 1973, mentally handicapped people have in-residential facilities, and day activity centers, which has frequently meant a direct political relationship between the social service board and the mentally handicapped, sometimes with and sometimes without the representatives of the parents. Increasingly, there are handicapped persons on the boards and panels. That has proven to be a very strengthening and matter-of-fact development that has been very valuable and will have increased importance in the future.

Barb Goode: I am past President of People First in British Columbia, Canada. Recommendations that we have for the 80s include the following:

- 1. That we be asked what we want done and to be said on our behalf.
- 2. We should have education in public speaking in the classroom, night-school within a self-advocacy group, and learn basic writing skills.
- 3. We would like workshops on matters that concern us, such as sterilization, or anything that we feel strongly about.
- 4. People in workshops are working in the community and should get more money. As it stands now, we are not getting paid very much for sometimes doing the very same old thing day after day. We should be paid at least minimum wage.
- 5. More People First groups started everywhere.
- 6. Be on local boards as advisors or board members and to have a person to help other persons understand; also that the board would have to listen to us.
- 7. More chances to speak at conferences such as this.

Jo Dickey: The 1960s were a time of very heavy frustration for parents and people who live with the handicapped. There were no services and we had to start services to prove that it could be done, to prove that our sons and daughters were indeed full beings. In the 70s, as Dr. Lafave has indicated, we were locked into services, and I wonder whether this step was welcomed by a lot of people who felt that the advocacy of parents was a very threatening role for parents to take on. Having done that in the 70s, I believe that we are going to see something guite different. Like Dr. Lafave, I do not have a formula to present but I will tell you that we do have a vision and a purpose and a commitment. The commitment is that we are going to change our roles, we are going to get out from under providing services, we are going to leave that to the proper authorities or proper community groups. Communities are going to deal with the services that are going to give our sons and daughters the best possible technical support as well as emotional support. This means, I believe, that communities will have self-determination, and it will be our neighbors who will be deciding for us and with us how best to deal with the needs of our sons and daughters. The further we get away from the son and daughter that we each have, the more inappropriate the decision is going to be. We are definitely going to ask for a part or a role within the planning because there again, when you know an individual, you try to interpret their needs. Sometimes we do not do a good job, but we at least want to be heard. If our sons or daughters can speak for themselves, they are the people who should be listened to, not me, the mother, nor our son's father.

It is hard to see such a change at this point because a lot of us are affiliated very strongly with associations and a lot of us are comfortable in that role. But in my country an awful lot of parents are saying "We want no part of paying the light bills, we want to make sure that someone else does it." In saying it, I guess we have tried everything. We have tried the monitoring role and I am not saying it has failed but it is not enough in itself. We have tried getting on committees, being part of planning—that is not enough because very often it is a token situation and we are not listened to. We have tried as individual parents to demand some services or an improvement in the quality of available services. It is so evident that so many of us fight our battles by ourselves for the simple reason that our child does not become violent along with 20 other children at that very moment, so we do not get together. The child does not have an appropriate program and it is a realization for a parent at the same time as 50 other people, so very often we find ourselves in isolation at that particular moment. It is our job of course, to do a better job of getting ourselves together. There is one thing that we feel very strongly about that will work for our needs: parents and families of the handicapped embrace basic values, the kinds of values that hold together a parent group. In my country, we regard a person with a handicap as a full citizen and we believe that everything that happens to that person should be planned on an individual basis. We see that he should be in his own community with the very best possible life-long services that he can have and that resemble the most normal circumstances. We also feel that there must be a fixed point of support for that person so that they are not going down tunnels just to be sent back to have to go down another tunnel. This is what happens to us as families and as people with a handicap. We feel that our children as adults but particularly young children, because the services are geared to them in the community so much, must have access to all the generic services. As an adult we must give them support to be part of the community. What I see and what I think the parents that I have had the privilege of working with see, is that the 1980s will be the time not for better services, not for access, not that we will be able to monitor, but that the individual son or daughter that we have has a right to every service that you and I enjoy as citizens of our own country.

Niels Erik Bank-Mikkelsen: I'll try briefly to tell you that we have changed our service system in Denmark and that we have great expectations of the new system for the 80s. Up to 1980, the State was completely responsible for all services for the retarded. We have now referred this responsibility to regional and local governments so that the services for the handicapped persons now come under the same authorities responsible for the services for the rest of the population. This reform was based on the following two conditions: the objectives of normalization should be maintained and fully realized, and there should be no reduction in the service level.

We believe the goal of normalization is most easily obtained when all citizens, including handicapped citizens, are served by the same authorities that we call administered integration and administered normalization. Up to now, our level of family service was considered relatively high on an international standard.! think we are about at the same level as in Sweden, maybe we do have a few more of the large institutions than in Sweden, but we are reducing them and hoping to have them completely broken down in the 80s. This reform, the normalization that we have, is in the social field and in the educational field, and of course in the health of the handicapped that we accept in the same state and same rights as other people. In the social legislation, we are talking of persons with considerable physical or mental handicaps, for whom we have special rights. We have not mentioned the words "mentally retarded"—it does not exist in our legislation anymore. We have given up categorization for very good reasons. First of all, it is almost impossible to give a correct diagnosis: there are many pupils and clients with multiple handicaps and it's often difficult to classify. Although we've given up categorization in the legislation, it will probably take time before we have given it up in practice. We have also given up registration of the mentally retarded. We had very precise and correct statistics—we knew exactly how many retarded persons were living in the country—but we gave this up because we don't feel there's any reason why we should have to register mentally retarded people. We are all equal people, there should not be special registers. When we switched from the State to local government, the central administration worked out a detailed service of existing resources—facilities, personnel, and money—and a 5-year plan to safeguard the present level of services. These 5-year plans are now approved by the respective government departments and cannot be changed without the approval of government. But it is not forbidden to make changes improving the service level, as opposed to other planning systems in Denmark, which must be followed.

The State paid ail the costs up to 1980. Instead of paying the same amount of money, but based on so-called objective criteria, what we call block-grants, we have this. We also have compulsory plans and the standards of service level, that cannot be lowered but can very well be bettered. We have broken down barriers between groups of handicaps, and between the handicapped and the rest of the community. This is based on the assumption of a positive attitude to handicapped persons as equal citizens. There has been a growing improvement of this attitude in Denmark in recent years. The policy of earlier years was isolation and concealing the problems in the State system so they were not solved where they should be, namely, as close to the authorities as possible. We believe in what we call closed democracy and we expect very much from this administrative form. The main feature is that all special legislation about special groups of handicaps is abolished. This is one policy for the 80s—to have no special legislation for special groups, but to have general legislation of social services, education, and health, comprising all citizens. Persons with special needs will receive s ervices according to the needs of each individual. This should insure equalization and individual service when the responsibility rests with the regular authorities. I think it will also result in an improvement in standards because there is an open-hearted interest toward problems in the field of handicapped in my country. We are a very small country and if we have a standard, the whole country will know of it.

Our problems are very different from yours, but I think that our principles could be used also in larger countries with more complicated administrative systems. My formula for the 80s is a full realization of the principle of normalization and I want to stress that Denmark is not immune to the idea for handicapped people. We are making progress in disbanding the large institutions. The great majority of people are living in single rooms, and we are now trying to formulate that the single room may not be enough but a small apartment should also be the right for handicapped people. This was a realization from normalization, as well as no registration in the field of mental retardation arid no special legislation for handicapped people. They will benefit from the general legislation in the country.

Burton Blatt: I am from Syracuse University, and sometimes I feel I've been in the field of mental retardation since shortly after the Civil War, but it's only been about 32 years.

"Formula for the 80s" can be thought of as something very simple, but also something very

complex to to achieve. It goes like this: let's permit people—all people—to live the normal lives that they are capable of living. That's the formula. Part of the formula is the idea that the future for the mentally retarded, the physically handicapped, the elderly, or other fragile people, is bound intimately to the future for all the rest of us, not separated in so far as the future. If it's going to be a good future for the handicapped, it has to be a good future for all people. Also bound to this idea is the hope that this may be the last time that anyone must meet to celebrate the International Year of Disabled Persons. Everyone likes to go to celebrations, but it's not any fun when you must come to a celebration in order to call attention to a problem that each of us spends our days worrying about. Often we aren't very much relieved of the terror and the unhappiness that confronts so many people today. If we are going to be successful in creating a society where all people can live as normal people, we'll have to look at history a little more seriously than we have.

When you look at our textbooks, textbooks written by our great professors, you can see that our professors don't take history very seriously. You read about the wild boy of Avignon and textbook after textbook has the same conclusion: that his teacher's goal was to teach a retarded child and prove that a retarded child can learn. But that couldn't have been his goal. Even 200 years ago, however, other people were teaching animals to dance and jump through flaming circles and count, so it wasn't such a mirac ulous trick that he achieved in teaching a retarded child to say a few words, and put on his clothes, and come in out of the cold. No, he had another idea. It wasn't that the retarded can learn, it's that all people can learn. When Rousseau wrote, *Em He*, the idea he had wasn't only that the child is noble, but that all people are noble.

I thought I would devote the rest of my comments to looking at the newpapers because they have something to teach us about this future society. In the morning paper today, we have a full page advertisement signed by thousands of lawyers asking us to help preserve equal justice, continue the independent legal services corporation, and provide legal services for people who are unable to afford their own legal services. I would support this, but you have to ask yourself, in the future society, do you want a society where we need thousands and thousands of lawyers, and litigation after litigation? Will we need a special public law—Public Law 94-142—to guarantee schooling for a group of children, when all of the rest of us were taken to school with our mothers, without the sheriff, without the advocate, without the lawyer, without threat from the school, without having to threaten the school, and in the most natural way we were permitted to come into the school; that's the kind of society that we need.

A week or two ago, Mr. David A. Stockman, our revered Director of the Office of Management and Budget, was asked "What will these poor people do if they don't have legal services, what will these hungry children do if they don't have school lunches, what will these handicapped do if they don't have programs guaranteed to them?" He replied, "I don't think that people are entitled to any services. I don't believe that there is any entitlement, any basic rights to legal services, or any other kinds of services. The ideal that's been established over the last 10 years, that almost every service that someone might need and like ought to be provided, financed by the government as a matter of right, is wrong." And I ask you, if the government is not in the business of providing services, if Mr. Stockman's office is not in the business of providing services, what are they there for? We get a little clue to this from an earlier headline: "Reagan Set to Plan \$32 Billion Increase in Military Outlets." And we see that the programs that are being taken away from the inner city, the programs that are being taken away from the handicapped, from elderly, from poor people, from needy people, people who the government, in its wisdom, is now saying are the undeserving poor. That money is not going to be put back into the taxpayers pocketbooks. It's going to be put back into the military.

And this came in the mail just recently, after 25 years of learning from Scandinavia, from our own Declaration of Independence and Constitution about equality for people, normalization and mainstreaming and equal rights: a press release from the Los Angeles school district detailing a contract for nearly \$5.9 million for construction of a high school for trainable mentally retarded and severely handicapped people. So after, P.L 94-142, and after all of our conferences and all of our promises, the great city of Los Angeles is building a segregated school for the handicapped in 1981.

What we have done with the most important problems in the world is we trivialize them, we make jokes about them, and then every year or so, we hold a Conference to make ourselves feel better. What is the answer? It really is very simple. All people are equally valuable as human beings. The agenda for the 80s is to convince ourselves that all people are equally valuable, all people are entitled to live in ordinary society, and all the rest is commentary.

Gunnar Dybwad: Burton Blatt has stated the agenda. The formula for the 80s must be optimism, based on our confidence in the potential of the persons with whom we are working, and the soundness and validity of the skills we ourselves have developed in assisting these individuals to a fuller life. I realize that as I'm saying this, our government has turned the International Year of Disabled Persons into an International Year Against Disabled Persons. Our government has turned against rehabilitation, doing away with the Rehabilitation Act of 1973, which was twice vetoed by President Nixon, and a third time enacted by Congress. One of President Nixon's vetoes was based on the fact that rehabilitation should be reserved for those who deserve it. We are against children, as a matter of government: we are now abolishing P.L 94-142, while, of course, the ultimate goal of 94-142, is that our work be abolished. Still, doing away with it at this time, is nothing short of catastrophe. Above all, our national government's turning away from human rights in the national field cannot but have a negative effect on other efforts to secure human rights for disabled persons.

One should never say never, there is always change, the dynamics of which so far have not become clear through scientific exploration, the limitations of which have been pointed out repeatedly. No one can predict when a person is born where the limits of that 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. We continue to try to apply measurements to intellectual functioning, behavior, and emotional maturity. But the inherent dignity of any human being, no matter how severely disabled, cannot be quantitatively assessed and to do so, in the name of ethics, as has recently been tried, is a mockery of the term. I have finally learned to challenge my psychological friends—who keep defending the use of intellectual measurements or I.Q.—with my insistence on an age Q., or a health quotient. Certainly health is every ounce as important in human life as intelligence. But if we would judge humanity by the health quotient, where would Franklin D. Roosevelt have ended up? Yet, my friends smile at my use of the term "Age Q." They seem superbly confident that the I.Q. is still a valid measurement.

Much of my most significant learning in the field of disability, I owe to parents of children with handicaps. But I am convinced that we must listen, to a far greater degree, to the individuals with a handicap. For a long time, we thought that those with a severe disability could not learn. Now we know that we did not know how to teach them. We must learn to listen, and while this is not an easy task for those whose hearing is going sour, we must try. This is a resource and potential that no government, not even Mr. Stockman, can take away from us. Our emphasis on working much more closely, and more realistically with the persons who present the challenges we want to meet, will sustain our optimism. We have a temporary setback in current attitudes, but perhaps during these years we can once again look to other countries. I represent the international movement of parents and families of children with handicaps, and there is a lot of inspiration to get from other places, what we cannot get from developments in our own country. I certainly shall persist in being an optimist, and I cannot believe—I will not believe—that the progress we have made during the past two decades can be wiped out by somebody who happened to have a political majority during an election. The verities will outlast the politics.

The Future for People With Special Meeds

Burton Blatt

Despite recent comparisons of human service budgets with the money spent for our military bands, we should not forget that we have also been spending an awful lot of money for services. Just before the dissolution of the Office of Education into a Department of Education, the then Department of Health, Education and Welfare was the third largest budget in the world after the U.S.S.R. and the People's Republic of China.

The remarks I have to make are very serious and I would not want you necessarily to judge the validity of what i am saying merely by how well I present the argument. There is a very beautiful ceremony on Yom Kippur when the cantor chants a song to God. He says to God, in.essence, "i'm going to try my best, I'm going to try and sing beautifully and clearly and articulately, and most importantly, I'm going to be as accurate as I can be. But don't judge these good people here on how well I perform; put the burden only on me." And so, I am asking you that.

These are very vexing times. The President has been shot, and for what reason? Zealots demanding independence for their country? Misguided patriots espousing this or that cause, or some lunatic seeking to save the world? No, we are told that the deed was done by a love-sick college dropout, who wanted to impress a Yale freshman, who did not know him, and did not want to know him. There is a story behind every incident, and one can not understand the story merely by trying to understand the facts. The story of the assassination attempt is incomprehensible if you consent to remain satisfied with the facts, it becomes more comprehensible, if not any less horrifying, and the culprit no less despicable, if you try to understand it in the context of the society—our society—that seems to be losing its values. A society where 13 and 14 year old children are portrayed in our best magazines and newpapers as sex symbols. And, a society where the Director of the Office of Management and Budget has said, "! don't think people are entitled to any services." A society where we are expected to save 40 billion dollars by taking free lunches away from children, and programs away from the handicapped, to be added to an already, some think, inflated defense budget. We seem to be a society bent on spoiling our land, polluting our atmosphere, even though we spend billions to send space craft there to inspect what we pollute. We foul our nests, and we turn away from those who need us. We seem to have forgotten the purposes of our revolution in 1776. We seem to have forgotten the purpose of any revolution, which has always been to care for the sick, for the elderly, for those in need.

There is a powerful story about a military commander during the Crusades, who went from town to town with his army, burning homes, killing people, and his officers who needed guidance, asked, "Who do we save, who do we kill?" The commander said, "Kill them all, and let God determine who are the Catholics." There is little reasonable about the political and social climate today. A soldier in the mess hall, who said Grace before his lunch, was asked by the man sitting next to him, "How can you bless this food?" And the soldier said, "I'm afraid not to."

I bless and pray for this government, because, I, too, am afraid not to. What will the debate be in the 80s? It will be the same debate of the 70s. It will be the debate concerning where people will live, where they will grow, where they will go to school, where they will make their lives. And we are asked to take sides on this debate. Even within this field are people who, at least for the moment, want to believe that we are all together in common cause. There are differences, we all know that.

Simply stated, the most important debate revolves around the demand for the deinstitutionalization or the integration of retarded people. And despite recognition everywhere, even among those who oppose it, that deinstitutionalization is the goal for the future, some still claim that institutions are appropriate places for severely and profoundly retarded persons. They claim that the deinstitutionalization movement has proceeded too quickly to prevent mere dumping, that we do not have the technical resources to make deinstitutionalization policies work for people. Of course, there is another view: that the barriers to deinstitutionalization are not technical, not medical, but in the heart; not in the mind, that they are not in our ability, but in the will. And frankly, they are also in the pocketbook and not in the Good Book. So there are some people who are against deinstitutionalization and what are they telling us? That the idea of deinstitutionalization is not grounded in an empirical base; that there are people so severely retarded that they cannot benefit from any sort of educational program; that they are "custodial;" that the community is not

prepared to integrate the profoundly and severely handicapped; that there is no evidence that the retarded develop more or better in normal communities; and that there are both good and bad institutions, and good and bad community settings, but that neither type of service is inherently good or bad. Institutions, they counter, provide more efficient and less expensive ways to provide a service to people with severe handicaps. Well the controversy—the debate—the agenda for the 80s concerns the validity of those contentions.

I have written too many books, given too many speeches and seen too much to be able to lay out all the evidence I have to refute these arguments. Even if I could, I do not think it necessary. Why did Lincoln free the slaves? Did Lincoln have evidence that the slaves benefitted more from liv ing in the community? Did Lincoln have evidence that the community was now ready to accept the slaves as free men and women? Did Lincoln have evidence that the slaves develop more and better as free people? Did he seek the advice of the Commissioner of Education, or the Norman Vincent Peale of the day, telling them that they would be happier in the community? Did he get advice from the leading economists of the day, saying that by freeing the slaves the Gross National Profit would rise, and we would get over our inflation or our depression, or any other financial hardship? No, of course he did not do any of those things. Lincoln freed the slaves because he became con vinced that all people in this country, who neither break the law nor are dangerous to society, deserve to be free.

If Lincoln could learn, so can the rest of us. Deinstitutionalization is not impeded by technical problems, nor any other problems. Purely and simply, the will of our people to recreate our society, for ourselves, for our children, for our grandchildren, in such a fashion that the handicapped, the elderly, and the fragile, can be free would be enough. Deinstitutionalization is being diffused by a failure of the spirit and not by any absence of evidence. There is no evidence for or against deinstitutionalization. This is a moral question we are struggling with, and not one amenable to scientific resolution. Anyone who tried to design the crucial experiment, to determine whether institutionalization or deinstitutionalization is better, would still come down to the question "What do you want for your society? What do you want for your children? What do you want for your grandchildren? You tell us and then you can do it."

Let us look at the so-called facts. Deinstitutionalization is little more than a slogan, when, to this day, thousands of people are unnecessarily institutionalized. That is only an estimate, not made by the so-called zealots, but by federal judges, by State Commissioners, by people who run those places. I daresay that even people who have debated in support of continuing the practice of institutionalizing human beings are saying today that most of the people in institutions today do not belong there. You have to ask the question, then why are they there? Some say people are so profoundly retarded that they can not benefit from any educational program. What, then, is the lesson to be learned from the Wild Boy of Avignon? That all human beings can learn. What is the lesson to be learned from that great saga, the life of Helen Keller? That people can learn. She has said in her own words that when she was 3 or 4 years old she was an animal; she could not eat by herself, she could not dress by herself, she was incompetent, she growled like an animal, she grabbled for her food. And the lesson to be learned is that before she became a great and magnificent world-famous person, before she went to Radcliffe College, before she wrote great books, her major agenda was to free the poor people.

We have the idea that people who are handicapped only have the handicapped on their minds. Capability is educable, and although we do not have a lot of evidence to prove that hypothesis, it seems it would be better for all of society, especially for the clinicians and those who work with the handicapped if we would behave as if people could learn.

What about the question of the community, that it is not being prepared to accept the profoundly retarded? Are we to perpetuate injustice? If that is the point, then the 13 million people who died in the ovens of Auschwitz and Buchenwald deserved to die there, because that was the belief of those who killed them. And all of the injustices against Blacks in the last 200 or 300 years of this civilization—we would be judging that they deserved those injustices, because that, too, was the will of the community.

If, today, parents of an ordinary child said "We don't want that child in our home, we will place that child in an orphanage," would the courts permit it? No. Sometimes society must do things beyond the wishes of the individual or the majority rule. Are the mentally retarded, are the handicapped, alone among all of the rest of us, immune from social policy? Some parents do not want to send their children to school. They are required to: that is the social policy of the country.

Then there is the question surrounding the assertion that there are good and bad institutions and good and bad community settings. Of course there are, but that is besides the point. Because there are bad universities along the road of knowledge does not mean that there can not be fine ones as well. And the idea that institutions are more efficient and less expensive than community settings: does anyone try to believe this? The per capita expenditure for institutionalization in New York State is at least \$35,000. institutionalization in New York City is a great deal more. And still there are children who go to bed in those institutions without pajamas, and wake up in the morning to be given some clothes that were not theirs yesterday and will not be theirs the next day.

I have been to scores and scores of institutions. My students have studied many, many institutions. We have 75,000 pages of data about institutional life. What have I seen? Dormitories for the severely mentally retarded, solitary confinement cells that are continuously filled with waiting lists for their use, not as many as in the old days, but they are still there. Scores of men and women, residents of state schools for 30, 40, 50 years. I have seen women sterilized, as a condition of their release from the state school. I have seen residents of the state school required to attend church services, and other residents prohibited from attending church services. I have seen residents of the state school perform essential work but not paid for their labor. There have been suits about all of these matters. But we do not need lawyers and court cases to guarantee our rights. That is the kind of future society that we are pointing towards. Our moral conscience has gone astray. I have seen children at the state school without any semblance of education, treatment, or training, yet it continues to be called a state school. I have seen residents who were stabbed, assaulted, raped, thrown out of windows, drugged, hurt in ways beyond description. I have seen children nude, bruised, sitting, sleeping, and eating with moist or dried feces covering them in their surroundings. I have seen children playing in and eating garbage. Why do we have euthanasia laws, "death with dignity" legislation? California has it, Florida has been trying to get it for a long time, all pointed at the fragile, the elderly, the severely disabled. What was once the rarest of exceptions is now becoming the law.