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NATIONAL ASSOCIATION FOR RETARDED CHILDREN, INC.
PUBLIC INSTITUTIONS WORKSHOP
October 5, 1960 Faribault State School and Hospital Faribault, Minnesota

Theme: CARE AND TRAINING OF THE VERY SEVERELY RETARDED IN INSTITUTIONS

Mrs. Max A. Murray, Chairman of the Section on Institutions of the National Association for Retarded Children welcomed the group to the workshop and expressed her appreciation for the hospitality extended by Dr. Engberg and his staff. She introduced Mrs. Hugh Johnston as the Local Arrangements Chairman for the day's program. Mrs. Johnston is the Institutions Chairman for the State of Minnesota, President of the Rice County Association for Retarded Children and a representative on the Private Institutions Committee for NARC. Mrs. Johnston welcomed the group to Faribault and stated she was very proud and happy that they could be present and to see this very fine institution. She then introduced the superintendent, Dr. E. J. Engberg.

Dr. Engberg: "It is with great pleasure that I welcome you and hope that what you see and learn will justify your trip here. I wish to greet you also from Commissioner Morris Hursh and from Dr. David J. Vail, Director of Medical Services of the Department of Public Welfare. They are attending a meeting of the Medical Advisory Committee today so cannot be with us. Miss Frances Coakley, Supervisor of the Section for Mentally Retarded and Epileptic in the Department of Welfare, unfortunately, cannot be with us today, but she wanted me to greet you most cordially.

Our program today is on the institutional care and training of the very severely retarded. We have arranged tours during which you will have an opportunity to observe our programs in operation. We have not planned anything different from our regular routine today as we believe you will want to see programs in the ordinary settings. I'm going to try to complete my talk early enough so that there will still be an opportunity to observe one of the activities for very severely retarded in the auditorium as you leave here for the tours. Among those in that activity is one who has an I.Q. as low as 16 and included are a great many wheel chair patients. These patients come from dormitory buildings over the campus to the central auditorium. You will be especially interested to learn that there are six volunteers who are with that group this morning and who come according to a regular schedule from Mankato which is about 50 miles from here to participate in this activity. I believe each of you received a booklet on your trip down here giving a general description of the institution so shall not repeat information that is contained in it. I think, though, that it would be well to emphasize that the commitment in Minnesota for the mentally retarded differs from that in most states in that commitment is not to the institution but to the Commissioner of Public Welfare so the individual committed becomes a ward of the state. That does not mean that the family is disregarded as we desire and encourage families and friends to continue an active interest in our patients. Commitment is primarily intended to serve the welfare of the ward, but when space becomes available—at present there is a waiting list of between 1,000 and 1,200—for a child or adult requiring institutional care, the Commissioner, in conference with the County Welfare Board of residence, determines whether institutional care is necessary at the time and, if so, authorizes it.

Here in Minnesota individuals of school age, or about from 8 to 18, who are educable, having no serious additional handicaps, and who, when they will have completed their training, are expected to become self-supporting, go to the Owatonna State School. Their program is entirely a residential school program as those of you who will visit there will observe. All others go to either one of three institutions--to Faribault if they are from the southern counties in the state, to Cambridge if they are from the northeastern counties in the state, or to the Brainerd State School and Hospital, which is in the northwestern part of the state, if they are from the counties of that area. We have a population of about 3,300 including about 110 at the Lake Owasso Children's Home which is about 5 miles from the State Capitol in St. Paul, and is operated as an annex of this institution. Cambridge has a population of about 2,000. Brainerd now has about 500 beds but is planned to expand to an ultimate capacity of 2,000.

It is a little difficult to define the entire group that we should be considering today. I think that we should consider it from the standpoint of essentially two groups. One is the group having severe multiple physical handicaps as well and those requiring constant bed care. In addition to these there is a portion of this group of the very severely retarded that could be looked upon as a custodial group. We recently received a questionnaire from Dr. Smith, the Superintendent of the Joseph H. Ladd School in Rhode Island. He stated that at the northeastern regional meeting of the A.A.M.D. later this month one of the subjects that is receiving their special attention is the education of severely retarded. Dr. Smith described the custodial as those who are not regarded as educable or trainable and with I.Q.'s of less than 30, without gross physical handicaps. I thought you would be interested in a description of some patients in this group with I.Q.'s of 30 or less. Our patient placement officer gave me summaries of a few of them. [redacted] Q., 41 years of age, has a mental age of 4.3, an I.Q. of 28. He works in the laundry sorting soiled clothes, loading and unloading both washers and spin driers and is able to start and stop them. He has worked in the laundry for over 10 years and is a fine worker requiring minimal supervision. [redacted]., age 38, has an I.Q. of 31. She works in the laundry in the clean sorting room where she sorts, folds and sacks clean laundry. [redacted]. works in a female infirmary where she helps bathe, feed and, as we term it, 'special' the patients. [redacted]. has an I.Q. of 21 and is 40 years old. Part of the time [redacted] works days and at other times nights. As a night patient helper she changes untidy patients as well as their bedding. When working days she helps feed and take care of the crippled and helpless patients. These demonstrate that with careful selection and careful training valuable patient help can be developed in this group of very severely retarded. I believe attention to this phase of institutional programming is important not only for the work they do but because they are healthier and happier as a result of it.

I was interested in the following statement in the annual report of the Board of Directors of the Rome State School in New York for 1958 which came just a couple of days ago: 'The admission rate of babies under five continues to increase as well as the public demand for the care of these infants in state institutions.' Probably less true here in Minnesota as the family or the county welfare boards must provide boarding home or private institutional care if it is not possible to care for the committed young infant in the home, until institutional space becomes available. I think it is well to call attention to the fact that in Minnesota it does not mean that just because the patient has been committed and been placed on the waiting list that he will be admitted automatically to the institution when his name is reached on the waiting list. If the care that the committed individual needs can be provided adequately at the time in the local community either in his own home or elsewhere when institutional space becomes available, the infant or the adult remains in the community. However, we are having a great increase in the number of children admitted under 10 years very severely retarded and among them many with serious physical handicaps as well. The report of the Rome State School continued: 'The majority of these babies present marked physical and mental disabilities and require constant medical and nursing care.' I was especially interested in this statement in view of our own experience and in having read the very fine article by Dr. Dybwad which appeared in Children Limited several months ago and in which he raised the question as to whether there still is a need for institutions for mentally retarded. I think as you make your trip through the buildings today and see this group of severely retarded patients, you're going to realize that it would be pretty difficult to take care of them except in a specialized institutional setting. I doubt very much that you will leave believing the day is right at hand when there is no longer a need for state institutions for their treatment, training and care. That being true, is it not essential that all the facilities and staffing be provided including everything else required to meet their total needs?

Our program consists first of all of making a very careful and complete diagnosis. We have the facilities here to do all the laboratory tests, x-ray tests and EEG tracings as indicated. We have consultants who are available to our medical staff to make interpretations of difficult cases. We have the further advantage if a case presents a particularly difficult diagnostic problem that we can arrange for the patient to be seen at the Rochester State Hospital where they have the facilities for even the deep EEG studies within the brain tissue itself. We feel that all patients deserve everything in the way of diagnostic procedures that is possible and that treatment, education, training and activities should be for the individual child or patient. I am sure somebody is going to raise the question of our educational program for this group. We believe we should plan to meet the educational needs and potentials of the individual. We attempt to bring into the program all of the facilities that we have, the activities program, the educational department, the chaplaincy program, the volunteer program, as well as that of aides in daily living experiences and the supervisors of patient workers. In other words, this group should receive fully as much attention as others brighter and more capable. To do this presents many problems, I am sure you all realize. We try to do everything to favor normal development processes to operate as these are important and can be helpful to us. We must recognize existing limitations but should not fail to look for whatever special abilities may be present and, even though these are minimal, we should develop them as much as possible. From the cases that I cited that are in the work program, you can see that this can be very rewarding both for the individual and for the institution.

Our immunization program is complete, applies to all patients here and is particularly necessary for the group we are considering today. We have an effective tuberculosis control program including an annual chest x-ray of all patients and employees. In addition we maintain a list of all negative Mantoux patients which is repeated annually. As a result active tuberculosis has ceased to be a serious problem here. Special attention is paid by the dental staff, consisting of three full time resident dentists each having an assistant, who see these patients immediately following their admission to the hospital if necessary or soon after transfer to their dormitories. Thereafter all patients are all seen at least once a year in order to keep mouths in the best possible conditions. An effort is made to preserve the teeth of the group we are considering today just as carefully as for brighter ones. In other words, our program here does not neglect these patients; it considers them and meeting their needs as fully as possible an essential part of our program.

We will now break up into the various groups to start the tours. I suggest that each group select a reporter who can make a brief report when you return and we reassemble. As you visit the buildings there are some things I wish you to observe particularly. All buildings including those for the very severely retarded have TV sets. Many of the buildings and especially those whose patients cannot readily leave them have speakers in the day rooms, dining rooms and other areas with a central control so that selected records can be played. The TV sets, speakers and recorders all have been donated to the institution by individuals and various groups including many by the local Associations for Retarded Children. This pamphlet that you received was printed by the Association. We did not have the money for it; when they learned this they provided it. We have an excellent Rice County chapter that works very, very closely with us. Mrs. Johnston who introduced me is very active in that organization and is this year's president.

I hope you will find that the tours you are about to take will prove interesting and urge you to be prepared to ask questions when we reassemble about what you have seen and to make comments on what has met with your approval or any deficiencies you may have observed."

Following the tours the groups met in the auditorium for discussion of questions regarding the Faribault program. Before the reporter for each group gave a report of the tour made, Dr. Engberg described briefly the institution's plan of organization. He stated that we have a Director of Administrative Services and one of Clinical Services, but that the institution is broken down into five sections. It might be said that we have four institutions within the main institution each having from 600 to 800 patients in each division as we call them with a registered nurse as the division supervisor. The fifth unit is the hospital which is handled as a separate unit. A Supervisor of Nursing Services coordinates the total patient care program. Thereafter the following reports were made:

Group I - The reporter was highly impressed with the small percentage of employees per patient and the high level of care, attention and treatment given to the residents. He was interested in our buildings and was particularly impressed with the hospital.

Group II - The group as a whole agreed that all of the buildings were amazingly clean and very well kept and the patients seemed to be very happy. The question was raised when they visited Poppy, which houses hyperactive girls ranging in age 15 to 65, as to why there was this wide range in years and were told that the patients are grouped according to their needs as well as their ages. The point was brought out that there is a doctor assigned to each building and that he may have as many as 8 or 10 buildings. A registered nurse is assigned to each division

Group III - Eleven people representing nine states were in this group. One of the first questions that was asked was who keeps the buildings so clean. They were very interested in Birch building which is one of our newest buildings housing 25 patients in each wing.

Group IV - They toured Spruce, Maple and Seneca. Spruce houses about 106 little girls between the age of 3 and 22. They were pleased to see the activities going on in the ward area. They were interested to learn of the underground and overland delivery of food. They visited Maple which houses 104 adolescent boys, ages 6 to 23. Their bedrooms were upstairs and play area downstairs. They observed the activities for these children. The last building visited was Seneca which is for infirm men between the ages of 16 and 77. This is a brand new, beautifully planned building. Here again the nurses area can see three different parts of the building, the dayroom and the two bedroom wings. They were very impressed with the appearance and cleanliness of all of the facilities visited. They thought the people working with the children on the wards were wonderful; there was a warm feeling and wonderful atmosphere in each of the wards. They also appreciated seeing the number of patient help and felt that this was a wonderful thing for them. They were pleased with the activities planned for these children. They inquired about the pay range for the psychiatric aide and whether we felt in any way that we have increased problems with dysentery or any communicable diseases by having patient help.

Group V - They visited Maple building which houses hyperactive boys, Birch building which is a girls' infirmary, age 17 - 93, and Pine building for boys from 2 to 15 having 111 patients. They were very impressed with the cleanliness. The reporter was personally impressed with the number of physically handicapped patients and the competency of the staff.

Group VI - They visited Holly, Maple and Poppy. They were very impressed with the patient help, their efficiency and pride in their work. They were interested in the use of tranquilizers in establishing better controls. They felt that the activities program was very well planned. They were pleased to have the opportunity to visit the severely handicapped section as those are the ones they often do not see.

Group VII - They visited the classrooms and O.T. Department and Handicraft and were delighted with the equipment there. They went through Pine for small boys and thought the children were so happy. They visited Holly building also and were interested in the use of tranquilizers. They visited with Dr. Bruhl and were interested in the PKU research.

Dr. Engberg then answered the questions that were raised. In reply to the first question as to who keeps the buildings clean, it is done in part by the aides and custodial workers but much of the work is done by patients. The charge aide in each building is responsible for maintaining it in proper condition during each shift.

He stated mention was made of the overland delivery contrasted to the underground delivery of food. The original plan for the delivery of food here was for underground delivery from the central kitchen to each of the buildings and there are tunnels that serve that purpose. At the time the institution had about 1,000 patients, this system functioned in a satisfactory manner. We are getting away from it now, hoping that ultimately we will have entirely overland delivery.

Mention was made about the new buildings. Dr. Engberg stated that we feel that these two newest buildings, Birch and Seneca, are the type of building that can be a standardized form of building for all institutions either mentally ill or mentally retarded. It is a building that can be used for any type or age of patient, except for a hyperactive, destructive type of patient. We who now are going through the experience of a tremendous admission rate from waiting lists can realize how helpful it is to us to have some buildings of this type. We have just completed transferring about 300 adult, ambulatory patients, many of them our best workers, to the new institution in Brainerd. Replacements were made from the waiting list and most of them are children under ten years of age. Many of these are very helpless. If a building is flexible, it helps to meet many of the problems that otherwise are almost impossible to meet adequately if sudden changes in the type of admissions occur.

The wage range for the Psychiatric Aide I is $260 - $316, for the Aide II $292 - $356, for the Aide III $343 - $416 and for the Aide IV $385 - $468. Dr. Engberg explained that we are replacing Aides III and IV by registered nurses as vacancies occur. He also mentioned that we employ new employees as Aide Trainees who receive in-service training for one year before they are appointed as Psychiatric Aide I. We have two registered nurses who conduct this program.

The question was raised in regard to infectious hepatitis and diarrhea. These diseases are a real problem in every institution where there are large numbers of young children. We're on the alert constantly and if a case of diarrhea develops, stool specimens are sent in to determine whether it is a case of an infectious type of diarrhea. If so, there is isolation and special treatment is given. Isolation continues until three negative stool reports are received. Infectious hepatitis is a problem here at present as it is in a great many institutions. Dr. Engberg stated he was interested in seeing a recent U.S. Public Health report which indicated that there had been over 60% increase of infectious hepatitis throughout the nation. We have certain buildings that we know probably have carriers because cases have occurred in them recently and it is our policy to give gamma globulin to all patients before they are placed in them. If infectious hepatitis develops in a building gamma globulin is given as a prophylatic to the other patients residing in it and to employees working in the building. If hepatitis is suspected, the differential diagnoses are made to determine whether it is infectious hepatitis whereupon isolation is carried out until recovery has occurred.

Mrs. Murray opened the afternoon session with her expression of appreciation for the wonderful cooperation received from the staff at Faribault. She stated that in past years the institutional workshops at NARC Conventions have been devoted primarily to the educable program, the trainable or the upper group of children but specific attention has never been given to those that were severely retarded. Since it seems that the trend is moving in the direction of more severely retarded children in the institution, it was felt that it would be very valuable to devote the entire workshop to this particular group of children. We are developing community programs to meet the needs of the educable and high level of trainable children so many of these children are remaining at home and in the future probably a larger percentage of the children in the institutions will be in this lower level.

She introduced several other guests attending the workshops, namely, Dr. Louis Bellinson, Assistant Director of Mental Health, State of Missouri; Edward L. Johnstone, President of the American Association on Mental Deficiency, and also President of The Woods Schools in Langhorne, Pennsylvania; Mr. Robert Porter, Superintendent of the Fircrest School, Seattle, Washington; Mrs. McGroth, Executive Director of the Canadian Association for Retarded Children and Mrs. Kleinstuber, Institutions Chairman for the Canadian Association.

Mrs. Murray then introduced the first speaker on the panel, Mr. Howard Huelster, immediate Past President of St. Paul ARC, and member of the Board of Directors for the Minnesota Association for Retarded Children. Mr. Huelster is the parent of a retarded child. His presentation "What Do Parents Want and Expect of A Residential Center Providing Care for the Very Severely Retarded Child" was the following:

"Mrs. Murray, distinguished guests, fellow parents, interested professionals, everybody, good afternoon. I have been trying to decide for several weeks now why the choice fell on me for this talk today. After considering several possible answers, I have concluded that the kindest answer is that it was the operation of inscrutable forces. Certainly it does not reflect any particular competence on my part to speak on this particular subject. However, I was asked, and I said, 'yes.' So here goes.

I classify myself, in the last year or so, as a parent who has passed through the three stages into a fourth, which is not defined in that famous pamphlet, <u>The Three Stages</u>. This fourth stage is a sort of <u>limbo</u>; it is the stage for parents who think that they are <u>in</u> the third stage already but then realize that they aren't anywhere <u>near</u> there yet. I think that I'm more unsettled now that I'm approaching my tenth year of retarded parenthood than I have been before, except for those first awful years. I realized this stage sharply about a year ago in Cincinnati when I fell into conversation with a young couple who had a child and a situation somewhat like our own, but who were much newer to this all at the time than I was. I thought that I was able to shrug off the incredulous reaction of another parent who had come to a different decision, who wonders out loud, involuntarily, how on earth you could have been cruel enough to do what you have done. But I found that I couldn't. The whole question of my decision and its rightness was opened up wide when that young woman marched on down the hall, leaving that beast of a man standing by the elevator, not quite sure whether he wanted to go up or down.

Thinking of that incident made me realize that I couldn't speak for all parents in my situation. So what I am going to say doesn't represent a careful sociological survey of 103 carefully selected persons representing a sample typical of all the parents of severely retarded children in institutions in Minnesota. Nor have I talked informally with many other such parents. These are the reflections of a parent whose child has been in a variety of facilities and whose work as an active member of the parents movement has taken him into the state institutions at various times and with varying degrees of thoroughness.

Our boy left home at a few months short of one year. We had not pampered him too much in order to prepare him for the distant future in a state institution. He spent the day in our playpen dressed in short pants and booties, draughts and all. When space suddenly opened up at a county boarding home we were advised to take it and we took him out and entrusted him to the arms of one of the largest, most loving of foster mothers a child could ever have. He was popped into long stockings and settled into the 80° environment of a private home with a dozen other children like himself and a large family of what the anthropologists call the 'extended' sort took him in.

After about a year space opened up at a temporary facility in the northern part of the state. This consisted of one of three cottages at a girls' correctional facility which were temporarily vacant. We had our child fed well so that he wouldn't get hungry on the trip; then we set out with father holding the boy. Shortly before we got there our overloaded and carsick baby threw up all over papa. We arrived apprehensive of the reception our smelly one would get. The aide who came to meet us at the door took one look at us, said, 'Here's our new little one,' wrapped child, smell and all, in her arms and welcomed him. He was there for three years, in a cottage of 35 children, with many aides and much close care.

In time enough young ladies were sufficiently delinquent so that our children were moved down here to Faribault. My boy went to a cottage, took sick, went to the hospital, was cured but continued to live in the hospital for a while, and now is back in a cottage of about 105. As we have visited him over the years we have had a chance to see him in a variety of patient care situations.

When we first were told that our baby might be retarded, I joined a sociology class at school in an annual tour of this institution. Later on I was on the legislative committee of our state association and had a carefully conducted and exhaustively thorough tour of the three major state institutions, those at Faribault, Cambridge, and Owatonna.

Frankly, then, when I was asked to speak to the question of what the parent wants of the institution, I was stumped. Our frontier days in institutional care are long since past. The day in which we live is one in which all social institutions--business, educational, religious, military, governmental--are extremely complex things. All aspects of care have been studied; a great deal is known; future long range planning has received tremendous investments of brain power all during this century. Now man's brain is being extended by electronic brains and automated thinking. The extent of future planning has gone from a few years to five, ten or fifteen years ahead. Our state government has long range building plans that go at least ten years into the future. Where basic minimum care is not present, its absence does not reflect an absence of knowledge of what to do; it much more likely reflects the lack of resources with which to do and a lack of public understanding of the retarded sufficient to support an adequate program. I bet that there aren't any problems known to an administrator of a hospital such as this that a legislature couldn't cure with money.

A social work supervisor from my home county said once, at a meeting where I was present, that she felt that my wife and I had gotten an ideal kind of community service at the time that our child was diagnosed. Our obstetrician was alerted by the delivery room nurses; he in turn called in a pediatrician who had been on the consulting staff here at Faribault and had had a lot of experience. We happen to go to a church with a clergyman who had been in touch with the parents movement and understood mental health programs and programs for the mentally handicapped. We were given what help he could give; we were alerted to the existence of the parents group and contacted it when we felt ready. We were presented with all the facts at the disposal of these varied groups. Our decision was our own, we arrived at one relatively early, and our child left home relatively early. We sent him because we felt that, because of our situation, he would receive better care. In addition he would be with his own sort. We were told by our social worker that the institution would be best for him. I think that what I want from the institution is continuing proof that our decision was right.

If he had stayed at home, we would have given him the most tender loving care that we could. We want the institution to give the most TLC, as the nurses call it, that it can. Since we could not do it alone even then we would have called on the community for support. Since the institution cannot do it alone I would want it to call for support, speaking vigorously to the state government, the legislature and the public of its needs. Since the care of such a child is so different from that of other children, I would want the institution to seek ever better ways of care.

But most of all I would want the institution to pioneer on some new frontiers. Totally different approaches might provide some entirely new visions of what the institution can do for the severely retarded. Every now and then I run into a tough-minded member of society, like a lawyer friend of mine, who has asked me several times why I keep my child alive. Would it not be better for society, for example, to eliminate this problem through some peaceful medical means as soon as a severely retarded child is born. I happen to belong to a religious group which is not able to give the customary answer which more traditional religions can give. Since most of my child's life has been lived in an institution of some sort, I have to depend on the institution people to answer that one.

Our children are so much the product of the environment in which they live that I would like to see some imaginative experimentation tried which would allow my child to demonstrate to me just what it means to be a human being of the severely retarded sort. It's not just enough to keep him alive. What is there, what sort of a being is he?

A different approach might be to ask and try to answer the question, 'what is happiness for such a child?' Since he has so little capacity for other things, and he does seem to have a capacity for happiness, how can he be made more happy more frequently? What in the institutional environment can be manipulated to develop that aspect of his nature to whatever may be the limit of that capacity?

Another way might be to attempt to answer the question: In what way is this child a human being? Those who would have us destroy our children before they can bother society suggest that they are less than human, that they are perhaps nearer to plant than to animal life. How can they be led to live in such a way that their humanity is never questioned?

This then is what I personally expect and hope from the institution--that it somehow live up to the promise that was made by social workers, and by the clergy and all those others who told us to institutionalize our child, who told us that he would be better off in an institution. What this parent expects of the residential institution is that it somehow provide a life for my child which will develop whatever potential he has for happiness, since I think that he has little potential for anything else. That this potential be explored to the uttermost, that new ways of living will be explored for him and those like him, rather than taking the traditional patterns of living and raising them to ever more efficient levels by perfecting present approaches to the care of the severely retarded. What I want to see is some pioneering in new horizons, for making some sort of new frontiers for our severely retarded children."

Mrs. Murray introduced the next speaker, Mr. Harvey A. Stevens, Superintendent of the Central Wisconsin Colony and Training School, Madison, Wisconsin. He formerly was principal at the Northern Colony and Training School, served as state supervisor for classes for the mentally retarded in the State of Wisconsin and later became superintendent of the Southern Colony and Training School. The Central Wisconsin Colony is set up primarily for the very severely retarded. Mr. Stevens' presentation was "Overcoming Some of the Practical Problems Involved in Setting Up An Adequate Program for the Very Severely Retarded":

"The topics that have been assigned to this panel to discuss are not easy ones to discuss. I am very pleased for the remarks that Mr. Huelster has made because it makes the introduction of the statement that I want to make much easier. The comments that I am going to make are not going to provide the solutions to the questions that he raised. While I seldom make apologies for what I have to say, I think at this time I should. I am sure that the impression you will take away from here is that I will be remembered for what I did not say. I am not going to talk about the desirable type of rooms, about single stories versus multiple stories, about ramps versus stairways, about the suitable kinds of building material, about the desirable types of heating systems, about the desirable number of square feet per patient, desirable playroom sizes, about security screens, about labor saving devices, problems of reduction of odors, selection of clothing, problems involved in feeding, in bathing and in toilet training, about problems involved in providing some emotional help for these children, about medical programs, about nursing programs, or about recreation or language development programs. All that I have enumerated for you are inherent, and are problems of the very severely retarded. This partial listing only serves to show you the complexity of the problem that confronts us. There is something much more basic. It is to you people as parents, as members of a society, that we must turn to help find the answers to this basic problem. This is the one that Mr. Huelster mentioned. If you have studied or reviewed the history of the concepts and philosophies that have gone into the development of programs for the severely retarded since the dawn of man, I think you might be appalled and surprised. I recently had an opportunity to read a book which described the children in primitive cultures. They dealt with this problem in a very harsh and cruel manner by today's standards. It probably was the way it had to be dealt with in those primitive societies. The attitudes and concepts that our society has today have come down to us from these primitive cultures. In the last 100 years we have unfortunately developed for this particular group a defeatist attitude. This is part of our culture, part of our heritage. Somehow or other we must find a way and a means to develop a positive attitude toward the very severely retarded. And it takes more than giving an institution the facilities or the personnel to do this job. This must be developed in the population of a given state. They must be willing to undertake to pay for the cost that will be required to provide the humane kind of care about which Mr. Huelster spoke. It is an expensive program. Mrs. Murray mentioned that the Central Colony was designed entirely for the very severely retarded. The people of the state of Wisconsin were told when it was first conceived to have this insitution that it would be costly, but yet they were willing to at least make a start to provide the kind of facilities and personnel so that we can give humane care. This defeatist attitude has resulted in inadequate facilities. We need not review this for you; you know what they are today. It has resulted, in many places, in putting the poorest trained personnel to care for this group. It has resulted in housing them in the poorest facilities, the poorest and most inadequate buildings. How can we, with a defeatist philosophy motivating these programs, ever hope to do a good job or to give them humane treatment? And probably much more important, and here is where the professionals have a job to do, we have to somehow re-educate the thinking of the professional people that we are not dealing with a hopeless individual. We have to point out to them that these individuals are members of the human race, not apart from it, and that these people have a right to be provided with the best facilities, with the best personnel and that we give them the benefit of the latest knowledge and techniques and skills that we have available in providing for their care. The educator is just as guilty as is the recreational person, as is the social worker, as is the physician. We're all guilty, or have been, for looking upon them as a group for which little could be done. Those of us who have been associated with the problem a long time have seen many evidences where we have literally relegated these individuals to the human scrap pile, if there is such a thing. You know and I know of many examples where modern surgical techniques have been denied to the very severely retarded individual because they felt that the technique would not improve him. This is wrong in many cases. The same thing has been true in the area of providing them with good nursing techniques. We were satisfied to accept substandard medical care or substandard nursing care. We would not stand up and ask for these programs because it was going to be costly. Strange as it may seem, the techniques are well known as to how to give these individuals good care. Because of this defeatist attitude, this do-nothingness, we have not placed these individuals in a stimulating environment. Because of a lack of stimulation, they have actually regressed. You could take a healthy, normal infant and place him in the kinds of situations that we place these children and in a few years you will have an individual who would behave as a very severely retarded child.

Another area that we need to give attention to is the study of the characteristics and, more particularly, the needs of these people. I think this is so important when we try to develop programs. For this I have to scold, shall I say, the professional people, because they have not taken the time to find out what these needs are. You cannot design programs or you cannot design facilities unless you do delineate these needs. This is a very complex population. It's far more complex than the trainable group or the educable group. There's an absence of language and speech in most cases and there is a large percentage of physical handicapping conditions. Over 40% of the population at Central Colony will be composed of severe physically handicapped CP's. There is a large percentage of epileptics. A large percentage are bedfast. And, incidently, because we have tolerated and permitted overcrowding, we have made many of these individuals bedfast for the rest of their life because we did not have space to exercise them. There are only a few who will be capable of complete self-care. A large percentage are diffucult feeders. In the present population at Central Colony, we have a large number who take anywhere from 30 to 45 minutes to feed. Only a few can respond to simple recreation. Many of them require complete help in bathing; many of them are on special diets or require mechanically altered foods. This group is prone to infections, susceptible to diseases. Many of them are in a debilitated condition. Somewhat at the risk of being criticized, I want to illustrate what has occurred in a state which has attempted to provide what was thought of to be a most modern facility for the very severely retarded. To me the group responsible for the planning and design of this building made some very gross errors. The first error is the one that Mr. Huelster mentioned, and which I have tried to emphasize, that these people are human beings and are deserving of the best kind of care and attention. The second basic error is that they did not delineate the needs accurately enough so that the architect could provide a design to meet these needs. Let me read to you a quotation which describes this facility. This is taken from the book 'Psychiatric Architect' and I quote from it: 'In place of the beds the wards have four unit stalls into which mattresses are placed. The inside walls will be marble. This will enable patients to be transported by means of a special cart to and from the bathing area without having to be lifted by personnel. The cart is a modified stretcher carrier with a hydraulic lift device which slides under the mattresses and raises the mattress and patient to a convenient height for wheeling. The beds are replaced in the stalls. The stalls are clustered in the center of a ward area. The cart also enables an ultra efficient bathing arrangement which one architect compared to a minute car wash. Instead of the attendant carrying the patient to a shower or bathtub, a method which invariably gets the attendant as wet as the patient, the patient will be taken on the cart to the sanitation center and sent through a bathing corridor. The corridor walls have guide rails so that the cart itself is held alongside the low counter where bathing attendant uses a hand nozzle to spray the patient and rinse off the soiled sheet. Completely waterproof mattress. The attendant then dries off the patient and changes the bedding. At the same time the cart will be dried by jets of warm air emanating from wall ducts. The linen will be placed in a laundry cart which will be stored in a heavily ventilated room near the service entrance.' I can think of nothing more impersonal than the description of this facility. They have violated every principle of good patient care. They have accomplished only one thing. Apparently it kept the attendant from getting wet.

You people have a responsibility to create different attitudes in our society towards the mentally retarded. You people have the responsibility to develop within the citizens of your state a social conscience that will provide these individuals with the kind of care for which we now have the known technique. This is a real challenge and your responsibility."

The next speaker was Mr. Bernard Dolnick, Superintendent of the Fort Wayne State School in Indiana. Mr. Dolnick's background is in Administration and he has been in this field for the past twelve years in one capacity or another. This is his fifth year at the Fort Wayne Training School. Mr. Dolnick's topic was on "Developing and Promoting a Philosophy Which Permits the Planning of an Adequate Residential Program for the Severely Retarded":

"Thank you, Mrs. Murray. I could quit right now because one of the penalties of being last on the panel program is that almost always your predecessors steal your subject, particularly when the topic is as generic as the one we have assigned today. I think Mr. Stevens covered my points perfectly and did a masterful job. We all agree on what is best. I think perhaps on the whole the philosophical concepts are not the basic objectives that are lost but rather some of these intermediary objectives and the timing. Most important, how do you bring it about? How do you promote it? I think at that point there is always a question of timing, the mobilizing of resources and what do we do now, instead of talking in platitudes. In this sense I might come to you with a fresh concept. In reading the literature, you've heard over and over again that we want, all of us, to develop the kind of a program which will maximize opportunities for happiness and productivity and self-expression for all levels of impairment - the higher functioning, the moderate, and the severely retarded. We want to give equal play on the institutional scene for all of them. And, as Harvey pointed out, perhaps our attitudes on a negative scale have held back too much in the past because, for many reasons, professional people and others have felt results are more visible when working with the higher functioning. And inadvertently, I suspect, that the programs, even though designed broadly for all, have bypassed these severely retarded.

I am very happy that we have somebody like Harvey Stevens because the records are very clear that he has a concern for promoting positive and progressive programs for the severely retarded. We all are interested in a complete program, of course, to provide the essentials, the safety factors - to provide an environment which is free of fire hazards, free of sanitation hazards, an environment where they are kept warm, well fed, comfortable, etc. But that is really not what we are primarily trying to develop. We have already done this to a great extent. Most institutions in the country have come to that point, even with limited resources. And I say 'even with limited resources' because of the dedication of people who have been working in the institutions. I'm talking of all levels of personnel who have worked over the years despite low salaries, long working hours, etc. They have by some magic, and I don't know the answer to it, brought up the level of day to day care to a point beyond expectations. But there is something much beyond that. Mr. Huelster very ably discussed the abstract connotation of happiness in an institutional setting. I, also, would like to mention this thing 'happiness'. What is this we are trying to measure or see? My best educated guess is that there is so much to do that any effort will make remarkable improvement, if we work on a basic premise that up to this date we have done very little in terms of involving the dignity of all of the residents in an institutional setting. It's very difficult for the outsider to think of all levels of handicapped people with a full right to an equal share of dignity. I'm reminded of the many questions I have received at the Fort Wayne State School. We have tours like you have here - daily, twice a day, and particularly now before the next General Assembly. We have frequent callers of ardent legislators, public officials, volunteers, educators, students, etc. I have attempted, as Mr. Huelster was working up his idea of happiness, to list some of the questions of the highest frequency which more or less relate to this point. The legislators, for example, visit at this time of the year and are taken to the worst facilities - ones that are most overcrowded, etc. I present the fire hazards, sanitation hazards, and he notices the severely handicapped, the multiple handicapped, and the first question he might present, 'Why do you think, Mr. Dolnick, that the dollars you are requesting for your program deserve a high priority in view of so many other desperate needs in our society today? The State has just so many tax dollars. We have problems of defense. We have the problem of highways. With all of these things, we have to be practical. You're asking for money which would strip our defense, etc.' And I like to tell them the story of the top notch scientist at Purdue University whom I visited several years ago, who brought up the same subject. Without belaboring the point, I referred to some basic philosophical concepts accounting for the fall of the Roman Empire. I hoped he would profit by this. What culture really survives in the final analysis? One that's geared to war and materialistic needs or one that's geared to maintaining human dignity for all?

In promoting a philosophy, I think you've got to work into your orientation program and any contacts you make with the staff, formally or informally, that what counts in the institution are these things over and above the health and sanitation needs. We at the State School, of course, fortunately or unfortunately, are able to escape the traditional terminology. We don't like to think of the people in the institution as patients primarily. Let's stop to analyze. Does a patient focus promote the limits of a program - that of primarily keeping them clean, healthy, warm, etc? I believe it does. We call our people 'residents', and we think of those during the course of a day needing medical attention and going to the hospital as patients - and they are patients, just like anyone in the community going to the hospital. Realistically, many of them, because of their high incidence of physical impairment, will be patients for a longer period of time. Some of them are chronic. I will recognize that too, but for how long? This is a very basic question. Happiness? How is happiness related to regarding them as patients or as residents? How do they feel when they come to the institution the very first day and are put into a hospital gown and mother and father can't see them for an entire month? They're thought of as patients immediately. We admit all of our children to the hospital in a special two-room suite. They keep their clothes unless they come from the home in a gown or in such a condition needing immediate medical attention. Mother and father can come the first day, stay part of the night, come the next day, come as often as they want, take them home the same day, take them home the next day. They are not patients; they are residents. This to me, if anything that I can possibly say, is most important. There's very little to say that's new, really. Many things have been said over and over again in the literature, in conferences, and by people with much more experience that I've had. I hope that the best thing we can do in our residential centers today is to start to think of the people as being more than patients."

The following questions were presented for discussion by the buzz groups:

Group I: How can parents and the institution develop a greater degree of understanding and mutual purpose?

Mr. Dolnick: I personally feel that the basic approach there would be to encourage the parents in the program proper, not just a token kind of approval but actually one with complete and wholesome participation, probably with a lot of education and counseling techniques and through the Associations for Retarded Children visiting the school, meetings with the staff, discuss their policy and return to their meetings with parents where there is general participation. Once a year they now have a recognition night where they provide entertainment and awards to the senior staff people for their efforts. One way is to really take them into the communication lines, whatever they are, formal or informal, through meetings, through letters, bulletins and the encouragement of visiting without any reservations and to state that you have an open door policy and to mean it. When they come to the institution and want to see a staff person, that person should be available to discuss their problems. We on a staff level should show extreme patience in this communications effort.

Group II: How do you feel about home care for the very severely retarded?

Mr. Stevens: There are many states which do have provisions of one plan or another for home care. Some of these are known as foster home care programs or family care programs. This is somewhat similar to programs which we have had for many years for the dependent and neglected child. In Wisconsin, we do have a family care program. The emphasis until recently has been upon placing primarily those of school age in the family care programs. Attempts are made to find a home in a community which has special class programs and where they could be enrolled. This has worked very successfully. We know that in other states they have been able to develop the family care program to even a greater degree. Michigan has had programs of this type and has been able to place a large number of adults. At the Central Colony, probably next week, we will make our first placement of a very severely, physically handicapped child. It is extremely difficult to find a home that will provide the kind of care that this individual requires. We cannot, of course, place out those whose needs are basically medical or require extensive nursing care. They require rather specialized facilities and few homes are capable of caring and giving this kind of care. There are a large number among the severely retarded whose care is much more of a chronic convalescent nature and homes can be found. It is my opinion that only those very severely retarded should remain in a residential institutional setting where their needs are basically medical or require extensive nursing.

Mr. Dolnick: I might only add that we should take close cognizance of other needs before we make any attempt to work out a plan for foster home care. We want to be sure that all the institution has to offer is being provided for the youngster and I'm thinking of speech and hearing, orthopedic, etc. Too often in our haste we say outside of the institution it is always the best but we want to be very careful to make sure that specialized needs are provided. If we look at the institutional setting in the concept that it is a place that relates back and forth, if we think of it as a continual service, even after placing in a home care setting, the ways are open for return just in case special medical needs are necessary. I would then say this kind of program will work very effectively. We also have a foster care program in Indiana but if you want to be very objective about it, we would find very often that unless you are very sure of your case work, the home might not be in the best kind for the youngster and just to say home care and not think of quality is very dangerous.

Group III: How can parents ask the attendants questions concerning their particular child? Some institutions do not want parents to ask questions of the attendants.

Mr. Stevens: Some institution may have regulations concerning the type of information that attendants may give to parents. I am sure that the institution is thinking of selective kinds of information. I don't think that you want to get from the attendant a statement concerning the physical condition of your child. This is not in the area of competency of the attendant and must be done by the medical people. I don't think you want certain psychological, emotional interpretations given to you by the attendant. This is up to the psychiatric social worker or the psychologist. I don't think you want information given to you regarding your child's academic achievement. This is not in the realm of the attendant's competency. I don't think that there are many institutions which would not be reluctant to have the attendants tell you about what the child does during the day. I think what we're concerned about is the competency of the person giving the information. We have seen where a parent will be talking to an attendant and the attendant will say, 'The child doesn't belong here.' The attendant doesn't have the basic information to even make such a statement and if he does he is in error. If you're looking for information concerning everyday activities of your child, I'm sure no superintendent would deny you this. What they are denying is that the attendant should not assume responsibilities which are far beyond his competency.

Mr. Dolnick: I agree, but I don't think an institution should set a policy which flatly denies the privilege of the parent to approach the attendant on any question. I think our responsibility is to educate the parent and the attendant as to the respective levels of competency because I think we'll get into a real difficult situation where to draw the line and in the final analysis we're going to shut down this feeling of the parent wanting to contact the attendant. You're closing out within the institution something that should be broader and bigger than all these parts that Harvey talked about. I would rather have the attendant make a mistake once in a while than to run the risk of setting up any kind of censure, although I do agree that it is best to understand the levels of competency.

Group IV: Mrs. Stevens, you told us a while ago of your objection to the mechanical bathing process. We, as a group, feel that if this process were inaugurated it would give the attendant more time for other kinds of therapy. Do you feel that this mechanical process is not humane or may we ask what is humane treatment?

Mr. Stevens: First of all let me say my reference was to the care of a very severely retarded person. Now, if you think for one moment that there isn't therapy in giving a very severely retarded child a bath, you are in error. One of our chief difficulties has been that we have not developed a one to one relationship between the patient and the person taking care of him. Some years ago I read a statement which said something like this, that the more scientific care given to a patient, the more emotional problems you're going to create. What they meant by scientific care is where you have removed the personal contact. There is opportunity for language development when a bath is being given. How many people here would want to be bathed in this fashion. You can employ people who can do the heavy lifting. There are a number of mechanical devices that you can wheel alongside the bed and lift them out onto a cart and carry them to a much better, more humane type of facility than this automatic car washing system. I think we have degraded, we have lost, we have ignored the dignity of this individual by putting him in this type of automation. These are human beings and I think we must respect their dignity. The reason that we've gone to this type of installation is in the guise of economy. I'm sure that in time if you keep a child going through this kind of bathing facility for many, many years, you're going to create problems. There is some interesting work being done in animal psychology. Many of you may have read or recently seen a television program on the work of Dr. Harry Harlow with rhesus monkeys at the University of Wisconsin. We do not know as yet whether his findings are applicable to human beings. We can suspect that what happens to individuals during the first five months of life sets the emotional pattern for many years to come. The more that you deny human contact, the more problems we create. There is more therapy in a bath where there is a one to one relationship than there ever will be in this automated bathing facility.

Mr. Dolnick: I think this can be illustrated in some other endeavor also outside the basic medical needs. For example, the usual way the severely retarded have been clothed in the institutions that are state supported, the prison-made shoe, the overalls, etc. Most of the institutions have gotten away from that. We try to individualize their behavior, their dress pattern, etc. but with an attempt to individualize further introduced the shopping center technique, where they come in and have the experience of shopping and the training that goes with it. We in our initial efforts thought that perhaps those of a higher level could come to the store but we made an attempt to bring the lower functioning youngsters to the store and we learned just by observing how stimulating that venture was. We saw very severely retarded marching to the clothing store, selecting and trying shoes on, and point to the shoes with a feeling of elation. This is a one to one relationship. They got more than just a new pair of shoes; they got some training and some relationships with staff and I think the same can be carried over to any endeavor in the institution, getting away from basic management to a program involved.

Group V: What types of research are carried out on residents and, particularly, is there any research on communications?

Mr. Stevens: I do not know of any specific research underway at the present time but I know of several institutions, ours is one of them, which will shortly undertake such a study. But there is much that can be done to develop communication between the very severely retarded and people who are caring for them. A very prominent speech therapist said that you should bathe your child in sound. This meant that from the time you first take care of the infant you should talk to them in soft voices. It doesn't make any difference what you say but you should talk. You begin to establish contact by getting the infant to understand that some type of communication is being made. We have been trying this at the Central Colony. One of the instructions that we give our nurses working with patients is to constantly talk to them and to observe them, particularly the cerebral palsy children to watch their eyes. We have found in a few cases that there is some kind of communication that can be made between the eyes. We have one attendant who can do it. Now I'm not saying that this can be done with all but this attendant has developed communication and he can get yes and no answers out of this very severely retarded child. One day it was agreed upon in a certain ward that everyone who walked past a particular patient would stop and say 'mama'. This happened during the feeding, during bathing, etc. And the interesting thing that happened was that the patient in the bed next to him first said 'mama'. We are the ones who must learn and we can do it through research.

Group VI: In regard to admittance procedures, wouldn't it be better to allow parents to see the child soon and taper off the adjustment period gradually? Most state institutions require complete severance with the child for a month or six weeks. Is this psychologically sound?

Mr. Dolnick: We don't know whether it is psychologically sound but we do it this way. If part of the basic problem is the adjustment of the family, then we certainly think it is psychologically sound. If it's a question of transition of a youngster from a home to the residential setting, we don't have any scientific data for you but they seem a lot happier. We feel that the parents do want it and we certainly have had success with it.

Group VII: If we take every 1,000,000 of our population and 3% are retarded, we have 30,000 retarded out of every million. A small number of these percentage-wise are cared for in our state institutions. Viewing the entire scope of the total program for the mentally retarded, how can we define the role of our state institutions in relationship to the total program and, bringing that further to a specific question, what is actually the goal of the programs in our state institutions so that a parent can get the answer when he asks what will my child receive from the program if sent to a state supported institution?

Mr. Stevens: My first reaction is to the 3% and my feeling is that this is too high. It is probably closer to somewhere between 1% and 2%. This is an academic question. One of the things that needs to be done soon, and you people have a responsibility to see that it is done in your own state, is that every state should develop first a total state program. Then you will recognize that the institution is only a segment of the total state program. Another aspect of a total program relates to the admission policy to these residential facilities. We need to change our philosophy. One of the current philosophies related to institutionalization is that a child or an adult should remain in his own home or in his own community so long as they are a better basis for his development than can be provided for in an institution. This is necessary if you want to have a good residential program. I think many people today recognize that the institutions are only part of a total program and that they should only serve certain kinds of mentally retarded individuals. But this then places a burden upon the community, and this is where it should be. The community must now organize itself to assist the family and keep as many of these as they can in the community. We should send only to the residential facilities those whose needs are better met in a residential setting. This is intensive care, this is costly care. The care at Central Colony is going to approach somewhere between $3,500 and $4,000 per patient per year. No home or community can provide this kind of care because they require such a wide variety of services.

Mr. Dolnick: I agree wholeheartedly that the role of the institution ought to be only a small part of the total program of the state. However, I think it is a most important one because of its contributions in research and training. I agree that we will see more and more severely retarded coming into our residential facilities. However, over the past years we've neglected quite a bit the needs of the socially maladjusted, needing desperately some kind of intensive treatment and training which a closed environment can possibly best provide, if we have staff and research opportunities for the attraction of staff.

Mrs. Murray expressed appreciation to Dr. Engberg and to the staff for the wonderful way plans had been made for the workshop and expressed thanks to the speakers for their contribution. She thanked Mrs. Johnston for making all the local arrangements and closed the session with these words:

"In closing this session let us for one moment focus our attention away from the severely retarded persons we have been considering to our own selves. Perhaps the real and most pertinent question facing us today and in the immediate future in regard to caring for the severely retarded is not so much what happens to him as what happens to us as human beings.

What happens to you and to me and to our legislators and to our governors--to society in general when we permit these, our brothers, to exist in conditions which are beneath the standards of human dignity which are his inherent right as a child of God?

The following words, written by Betty Hanson of Saginaw, Michigan, express so beautifully some of the goals and ideas toward which we have been struggling this day that we could hope they might be considered as a brief but basic philosophy by which we may be guided in the development of future programs for the severely retarded within our own individual states:

'We need the reverence for life to know that decent, humane surroundings and loving care are important, no matter how low the level of intelligence. Let no one be callous enough to remark that such little intelligence does not know so it doesn't really matter. This ruined child may not know but he is your brother and you know. Do not be afraid to speak for him when the time comes.'"