"Championing the Rights of the Retarded"

Address prepared for delivery by the Honorable Karl F. Rolvaag, Governor
Minnesota Association for Retarded Children, Inc.
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I want to talk to you this morning about some basic human rights. In all of my years in public service, I have worked to defend and protect human and civil rights and it was entirely logical that as I became acquainted with the severe neglect of the mentally retarded, I should seek to put the full force of my office into action.

I will recall the morning that your former President, Mel Heckt, and your Executive Director, Mr. Walsh, came to me to describe the conditions they knew so well. I was just preparing a presentation for the Women's Civil Rights Committee, to be made at a meeting in Minneapolis where the concern was focused on the rights of minority groups in our society. I drew the parallel then — as I intend to draw it again today — between the discrimination based on race, color and creed and that other discrimination that is not so well known or so familiar to society based on the handicap of retardation.

We have pushed hard to bring about change and progress, but not hard enough.

We have tried to shine the spotlight of public opinion into the dark corners of our neglect. We have made some gains — but not enough.

With my first term as Governor nearing its close, and a new legislative session ahead of us and much experience already chalked up, I come before you today with a declaration. I want to list for you eight essentials — eight basic rights of our mentally retarded fellow beings. We will not be put off. We will not be half-satisfied. We will not take second best — for "second best" people. Neither for them nor for ourselves nor for the integrity of our society nor for the well-being of our children.

We are determined to gain these rights. It will call for money, for ingenuity, leadership, tenacity, courage — whatever it will call for, we've got it. We're going to put it to work.

1. The right to live without privation.

This means an end to huge, ugly, crowded dormitories and dayrooms. It means a goal of no more than 4 persons to a sleeping room. It means pictures on the wall — pictures chosen by the patient — pictures that have meaning to him, that remind him of home or of the Beatles or of the ball club or whatever it is that counts with him. It means flowers on the window sills.

It means eating with utensils, and in an atmosphere of sociability, with no more than six persons — family size — sitting at the meal table. It means a drinking fountain or a water cooler — one that's not too high for little folk and not too low for big folk. And one that's in working condition.

It means privacy for bathing. It means a toilet bowl with a seat on it. It means ventilation and an end to overheating of buildings.

These are rights? To most of our society they sound so commonplace as to be amusing. But they are rights that have been denied to thousands of institutionalized persons.

Why?

Because it's easier to care for people in herds? It isn't.

Because it's Cheaper to build a dormitory for a hundred beds? It isn't.

Because you have to jam 40 people into a dayroom big enoughfor 14? We don't need to.

Because the mentally retarded don't know the difference ? They do.

The facts are that we will make better use of the same amount of construction money if. we do not build monstrous, sterile tombs and euphemistically call them schools and hospitals in a silly attempt to clear our consciences. The fact is that we get more out of small units, where staff can do a better job, where a person can retain his sense of worth, where he can begin to help us. Once the retarded person knows we want to help him live like a human being — he asks more of himself. We all do that.

I have been Governor for three years and two months. I have seen the people — my fellow human beings — who sleep in the overcrowded wards and live out their days in the stifling dayrooms. And I have felt the pang of personal shame. It is the right of each of them to live without such humiliation and privation. And it is not a right to be gained by bits and pieces.

2. The right to be useful.

At least six hours of each day everyone of us — including our retarded fellow beings — have a right to learn, to work, to be occupied. Our society revolves around work. The patient who is regarded as too ignorant or too helpless or too unstable to be included in activity programs responds by becoming ignorant. Or becoming helpless. Or becoming unstable.

"What can the dummies do?" I have heard the question many times. Make useful objects — for the hospital or for the community. Where is our American ingenuity we are so anxious to prate about? Where is our scientific technology, that we haven't got a hundred ideas for useful work for the retarded?

What else might they do? They can learn — they can be educated, gain skills. Where is our touted sense of educational commitment — that "every person in our society has the right to develop to his fullest capacity ?" This means getting your Ph.D. if you've got the bent for it. Or it may just mean learning to tie your own shoes. Or to tear foam rubber into bits for use as pillow stuffing. Equal opportunity for all means for all. And I am saying to you today that we must have a daily activity and educational and occupational program for the retarded that will guarantee them this opportunity.

We have made a few gains: the day activity centers, the workshops, the new MDTA program in the institutions, the new category in State Civil Service to employ the handicapped, the studies of patient-labor with a view to providing some decent remuneration. But we can't afford to go one step at a time! The retarded person cannot organize a march on Washington, he cannot lead a massive sit-in protest movement, he cannot lobby his legislator. He is depending on us.

3. The right to individualized care.

The most profoundly retarded child who for his whole lifetime may never do more than muster a smile from his crib has a right to love. To love and be loved.

Yes, during the last legislative session we won the largest increase in patient care personnel which has ever been achieved — 421 new positions. But today, Friday, June 10, 1966, we can go into a ward in one of our Minnesota state institutions and find it crowded, smelly, understaffed. We may find a helpless boy with his back deeply scratched and scored by a safety pin, inflicted by an unknowing and unsupervised fellow patient. We will see an adult patient doing her best — but her best is just not anywhere good enough — shoveling food into the mouth of a gagging bedfast patient unable to tell us of her needs. We can feel wet diapers, see soiled sheets. Most painful of all, we will have to turn away from outreaching hands and winning smiles, from fellow human beings who are withering up from loneliness. Tender loving care when you are helpless—that is the right I am talking about. The bedfast child needs it and so does every other human being. Someone has to care about you in order tor you to care about yourself. The way must be found to provide this kind of care: nursing homes in the community, small facilities where there is time, as well as interest, increased personnel in our state institutions.

It is estimated by the American Association for Mental Deficiency that one staff person is needed to care for three retarded persons. On that basis, given the current population of our state institutions, and assuming no increase, we need today 400 to 500 additional patient-care workers.

4. The right to be helped to the extent that help is needed.

If you've been born with limited abilities you have a right — a right which only those who have greater abilities can insure — to get a helping hand to find your way in the world. Ours is a dutiful and dedicated society. And we try to give that helping hand. The trouble is we often think we've done a job well, just because we've done something. We mistake action for accomplishment.

The fact is that help for the retarded takes many different forms. Putting a child in an institution may be a help but sometimes it may be just an empty gesture.

We must be sure that the programs we are devising — and paying for — are serving the need of the retarded persons. They must be a plus for him, a help. His needs are not static. A 10 year old may be ready for schooling. An adult, for a workshop. We must recognize far more fully the differences in each retarded person who is placed in an institution. Twenty-four hour care for the profoundly retarded on the one hand, and maximum freedom and independence for the less handicapped. Other countries have shown us the way. "Hostels, sheltered living, semi-independent units, halfway house" — we don't know just what to call it, but we know that we should be providing it. These fellow beings of ours aspire to "belong" — as do we all, and we owe it to them to help realize this aspiration.

I challenge our state institutions, our communities, our welfare agencies, our church groups, our legislators — and I promise to help them in whatever way may be needed — to develop suitable sheltered living units where the newly employed or habilitated retarded person can live — with some sense of security but also with some sense of freedom and independence. This may mean a new kind of facility in the community. It may mean a greater variety of living patterns within the institution. As we try to accomplish it, we must be guided by the full knowledge that each retarded person is different. Each must get the help he needs, but he must not be "labeled for life" or be "helped" into helplessness.

In enumerating these rights, I recognize — though time does not permit me to expand on it — that we have made outstanding gains in providing services for the retarded. Countless people, public servants, citizens, parents, political leaders — have given themselves, heart and hand, to the cause. The results have been far-reaching. But today is not a day for self-congratulation. We are taking stock, and we are heartsick at how much has been left undone. We are looking ahead — and we are staggered by the job that confronts us.

5. The right to free public education.

Last month I received a letter from a mother — mothers and fathers write often to their governor and from them I learn much.

"We live on an eighty-acre farm. All our children are gone from home except Mary who will be with us always," she wrote. " I have been taking Mary to a day school.. .every schoolday for the past six months. A distance of 68 miles round trip.. .it's getting harder every day with the outside work and field work to be done and I hate to take Mary out as her teacher said she is progressing real good.. .I don't see why they can't have a day school here in our town.. please answer. I will be waiting, waiting, waiting—how long!"

There are thousands of boys and girls like Mary in our state today, waiting. What are we going to do about it? Take another ten years ? They will have grown up! A child — a retarded child — any child — grows up only once. We are talking about a right that was set forth in our state constitution - the right to education. Why do we deny it? Every school district, every school board member in this state must take the steps now, this summer, this month — the steps necessary to provide educational opportunity to these children. They can learn! The younger ones can learn social skills, safety, the difference between "stop" and "go", cleanliness, acceptable behavior. The teenagers can learn to get to work on time, how to find their way downtown, how to respond to others. There is plenty that a retarded child can be taught — but he isn't going to learn it sitting in idleness, or in a regular class that measures him against brighter, more competitive, more aggressive schoolmates. I want to say to every educational resource in our state — to our state junior colleges, state colleges, state university, to the exciting new $10 million educational research laboratory, to the State Board of Education and the State Department of Education, to the 1400 local school systems — redouble your efforts to the end that the 17, 000 retarded children who are not now getting special education will no longer be so deprived.

In talking of the right to education, one may well include the day activity program. The business of solving human problems does not lend itself to simple definitions or mathematical clarity and we do not yet know how to define a daytime activity center. Is it education? Is it welfare? Is it health? To the parents of a retarded child the definition is not important — it's "what can be done to help my child" that counts.

As we set our sights on insuring this right to free public education, let us not forget the word free. For many, the cost of transportation to day activity centers is prohibitive. We have for years accepted the idea that the cost of transportation is as much a part of education as is the cost of tuition — for the normal child. The same equity is due the retarded child.

6. The right to acceptance as a human being.

It is somehow easier to assign a role to the social agency, to the school, to the state institution, to the county welfare board than it is to talk about people and their role. Over the back fence, at the drugstore, down on the beach, on the bus — it is people who make up our communities and it is their attitudes, perhaps more than anything else, which shape the lives of the retarded.

First we must increase public understanding of the meaning of retardation. We must eliminate the nonsense or myth. The simple facts about causes, incidence, preventive measures — and about the capabilities of the retarded, that they can be helped, that 85 percent of them can be in part or totally self-supporting.

The campaign has only begun: radio, television, schoolrooms, public libraries, statewide conferences — like the one to be held here in Minnesota in September. We cannot let up in this educational effort to open the eyes of the public to the facts of mental retardation.

At the same time, we will be creating the climate of acceptance. Everytime a normal person gets to know and help a retarded person, we have climbed another hurdle. Let us extend our normal activities to the handicapped — our public recreation programs, Sunday schools, neighborhood houses, playgrounds and swimming pools. Let us encourage the special gains that emerge from the vast volunteer program in the institutions for the retarded.

Knowledge, full involvement, both of these lead to willingness to support, to pay for the programs that I am talking about. We cannot bring these rights to the retarded without the full public support of all the people. No need to commend your organization for what you have accomplished in this regard. You know how much I admire and depend on you and look forward to working with you in the coming years, as we build public understanding of retardation and a massive public demand for a change.

7. The right to a job.

Employment on merit, that is all we ask — and we can accept no less. The retarded worker can prove himself if he gets the chance. Witness the young man now employed as a state civil service worker at Gillette State Hospital laundry — reliable, steady, conscientious. But for many years he lived out his days in a state institution for the retarded. Someone had to give him the chance.

Witness Carol, the 19 year old mentally retarded girl (described in the Minnesota ARC'S fine public information series "Minnesota on the March"). Carol's life was empty idleness until she came, six months ago, from a small northern town, to Opportunity Workshop. Today she's holding down an eight hour a day job, earning her room and board, and $200 a month.

Let us take our employer friends by the hand and introduce them to these young people so they can know that each retarded person is an individual, with individual differences, individual characteristics, individual abilities. Judge each on his merit, and we will find a place for each in our great productive society where our goal is full employment — including full employment for the retarded.

Sheltered workshops must multiply throughout the state, employers and labor unions must be persuaded to the worth of the handicapped worker, rehabilitation programs must reach out with imagination.and optimism. The right to a job must become a reality.

8. The right of every citizen to clarity and efficiency in the helping process.

This might seem a strange way to conclude the enumeration of basic rights of the retarded: "efficiency in government!"

But as we study the recommendations of the planning agencies, particularly the Mental Retardation Planning Council, we are uncomfortably aware of the shortcomings of how we deliver services to the handicapped.

How much duplication is there? How much coordination? How much difference between public service and private service?

How have we organized the structure, the framework through which we provide service and care? Has that structure permitted the best possible leadership to do the best possible job?

What kind of wages do we — the State of Minnesota — pay to the psychiatric technicians who staff our hospitals, to the faithful men and women doing impossible tasks, in an atmosphere of overwork and frustration?

How well do we utilize the staff? To what extent do we train them for the job and on the job?

How much do we teach future teachers or nurses or doctors or welfare workers?

How ingenious are we in maximizing the physical facilities at our command? How quick to utilize new approaches, shift to new patterns? I am thinking here of our mental health centers around the state and their potential as diagnostic centers for the handicapped retarded. I'm thinking of our state mental hospitals, strategically located in every region of our state, and now, for the first time in our history, serving a hospitalized mentally ill population which is less than the institutional population of retardates.

My friends, there is work ahead for all of us. It holds challenge and great promise.

We can build on the work already accomplished. While I have talked today about our problems and needs, I would not want it to appear that no one is doing anything about them. We know that they are: the wonderful people who man the wards and the dayrooms and the diagnostic services and the day activity centers and all the other agencies around our state. I strongly commend them. Not only for their dedication and devotion but for their willingness to look critically at their systems and their practices, for their openmindedness about changing, to make use of new concepts, to try out new ideas. It takes strong staff to be willing to attack "institutionalitis" and I want to personally thank each and every person who has worked toward that goal.

Yes, we can build on the present, and we have a lot of building to do. Let's get on with the job.