1969 LEGISLATIVE PROGRAM

MINNESOTA ASSOCIATION FOR RETARDED CHILDREN

\$.03 a day . . . that's what the cost will be... \$.03 a day for each adult Minnesotan . . . \$.03 a day buys the beginning of programs for mentally retarded persons ... \$.03 a day isn't much for a person . . . \$.03 a day will buy more for them, though . . . \$.03 a day won't buy all they need, but it will buy a beginning.

Who are we talking about? Well, their names might be Johnny and Jimmy -- you were always too deeply moved by the sight of them ever to ask about their names. They are brothers in a cottage for the profoundly retarded at a state institution for the retarded. As long as they live, they will bear a cruel burden -- locked in a world of blindness, consigned by a whim of chromosomes or an accident at birth to a life-long darkness of the mind. To them are denied all the pleasures and fulfillment of human kind--all save the most rudimentary joys of bathing in the warmth of the sun's rays, or savoring the foods they must be spoon fed, or feeling the comforts and compassion that a concerned state and their devoted attendants will always assure them.

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Then there's Helen, whose lovely face and graceful movements belie the tangled meshwork of ecstatic joys and piercing agonies that marks the autistic child. Is she mentally ill or is she mentally retarded? Perhaps she is both, perhaps she is neither. The wisest of diagnosticians and therapists have labored long to find the answers, but they do not know. They are not sure.

And there is Eddy, who stands astride the hazy line that separates the "retarded" from the "borderline" whose potential is-- or once was--considerable, but whose life has been one long, desolate, chain of failures and frustrations. Perhaps Eddy was born 35 years too soon.

Eddy is in his 40's. Those who have worked patiently with him fear that his life pattern may be too rigidly fixed. That life pattern is one of barely adequate job performance, punctuated every other week by drinking sprees. It is easy to understand the bouts with the liquor. They tell of Eddy's endless frustrations, of the jeers and jibes of which he has been the target a thousand times, of the constant reminders that he is "different", of the stark terror and the deep despair that are masked by Eddy's perenially smiling face.

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Mary is 21, with an I.Q. in the educable range. She is an only child. She has real promise for an independent future--if only someone could unravel the tangled web of her family relations.

No one could prevent Mary's ill-advised marriage. Those social workers at a welfare office tried. Almost every agency in her city has had a go at the tangled affairs of her family, with no success. Both parents need psychiatric counselling and neither will accept it. Without it, there is no way to cut through the cycle of rage and despair that Mary lives with every day of her life.

Steve, who lives a life of misery, has achieved at least one distinction--he has made worth-while material for eight social agencies in the state of Minnesota. All of these agencies counted his case a success. But Steve sits home, day after day, instead of attending the trainable class he belongs in. All of the agencies have done their jobs. Steve, however, sits home--without a class and without help.

Johnny and Jimmy, Helen and Eddy, Mary and Steve, all live outside the pale of hope and happiness. Science, on the verge of hurtling a man to the moon, unlocker of the secrets of the atom, miracle worker on a thousand spectacular fronts -- has not yet found ways to "save" Johnny, or Jimmy, or Helen, or Eddy, or Mary, or Steve. The humane and scientific revolutions of the post World War II years hold out more hope for the retarded than we, in our fondest dreams, could have conceived in a generation, perhaps even a decade ago.

But mental retardation is a congeries of more than 200 clinical entities, multiplied by an infinite array of permutations and commutations which must be understood and overcome before the tragedy of retardation can ever come to an end. Science and medicine move forward slowly. For each child spared a lifetime crippling of the mind by the conquest of PKU, there remain hundreds of Johnny's and Jimmy's, Helen's and Eddy's, Mary's and Steve's who must wait and wait and wait . . . and wait in vain.

Our state has made enormous forward strides in which it has every reason to be proud. But to the volunteer and professional in mental retardation, the moments of pride, the accolades, quickly evanesce. Always they give way to the ever present fact of the Johnny's and the Jimmy's, the Helen's and the Eddy's, the Mary's and the Steve's. Always the cruelty of their afflictions looms up to haunt and humble those who are devoting their lives to the mentally handicapped.

To the Johnny's and Jimmy's, the Helen's and Eddy's, the Mary's and Steve's, the Minnesota Association for Retarded Children dedicates its legislative program for 1969. And with that dedication is coupled a firm assurance that though they may not see, though they may not understand, the Johnny's, Jimmy's, Helen's, Eddy's, Mary's, and Steve's will always continue to power and inspire a ceaseless search for a brighter tomorrow through more progressive legislation.

Because of them, and the other 99, 996 people who suffer from a like handicap, the Minnesota Association for Retarded Children recommends the following legislative program:

SPECIAL EDUCATION

I. Increased Staff for the Section.

There are 20,617 children in the state of Minnesota who do not receive an education. Until such time as there is increased staff for the Section on Special Education, many will never receive the education to which they are entitled because the program of education will lack coordination, quality, development of new services, cooperative planning, and statewide support.

II. A Definitive Study of Special Education.

No study of special education has been done since 1955.

The Domian Report, "Education 1967", contributed little to an understanding of the problems of special education.

III. Report of School-Age Children Exempted or Excused From School and the Reason Why.

The Section on Special Education estimates 20, 617 mentally retarded children are not served by the educational system.

A count is needed to determine this figure accurately.

School districts are not required to report the number of children not served.

Such a census would determine needs, now and for the future.

IV. Remove Ceiling on State Aids for Personnel.

Additional aid would encourage more rapid expansion of programs,

Intention of 1957 law was that two-thirds of the personnel cost should come from the state.

The present ceiling of \$4,400 encourages employment of lower cost personnel whereas supervisory personnel and highly trained professionals are needed to insure specialized services and quality programs.

V. Mandatory Classes for the Trainable Retarded.

Why should a child with an I.Q. of 30 to 50 be discriminated against. Education is as vital for them as for the educable (50 to 75 I.Q.) child for whom classes are mandatory.

Trainable children of school age are excluded by law from daytime activity centers as the legislative intent was that the schools be responsible for education and training of school age children.

Of an estimated 9,000 trainable children, only 991 are being served by the schools.

The mandatory law for educable was passed in 1957 and has stimulated expansion three-fold in a decade.

STATE INSTITUTIONS

I. Equipment Requests.

Lack of equipment and supplies make it difficult for institutions to provide adequate care, treatment, and training.

Requests by ward personnel in our state institutions range from seats on toilets to comfortable mattresses, which are nothing less than a request from the administration to provide humane treatment for fellow human beings.

Requests ask for privacy in bathrooms and sleeping quarters to which every person is entitled.

Requests ask for sanitation measures to be taken to protect the health of the residents.

I. Equipment Requests (Continued)

Requests ask for recreational equipment to provide an outlet for a dull, unimaginative existence.

Institutionalized Minnesotans deserve to be treated as human beings by providing equipment which will help them to develop mentally, physically, and spiritually.

II. Increased Staff for State MR Institutions.

Insufficient staff means that for too many patients little more than custodial care is provided.

Lack of staff means fewer people habilitated.

Some residents regress due to the lack of stimulation and programs.

Many residents spend their lives in bed or in wheel chairs, because of staff shortages that allow little time for intensive training.

Better programs and training will be possible only with increased staff, both professional and non-professional.

Lack of staff perpetuates a rapid staff turn-over.

III. Increased Salary for Psychiatric Technicians.

The starting salary for a person who supports a family is barely above the poverty level.

Low pay and lack of staff, again, perpetuate a system of rapid staff turn-over. Vacancies exist in all hospitals because of inability to compete with industry on salary and working conditions.

IV. A New Metropolitan Residential Center for the Retarded Child.

There is no center in the Minneapolis-St. Paul area for retarded children and yet that is where over half the Minnesota population lives.

Children should be as close to their families as possible to make frequent visits possible.

Diagnostic and ancillary services are available.

The University of Minnesota and metropolitan hospitals would be available with supportive programs.

Housing residents should be in small Scandinavian-type units.

This center could be a model center for future regional development, providing a complete spectrum of services.

DAYTIME ACTIVITY CENTERS

I. We recommend the number of day activity centers be expanded and that funds be appropriated in the next biennium in the amount of \$2,500,000.

60 state supported centers now serve over 900 retarded people. Only 40 counties have such centers.

47 counties still have no DAC program.

Limited appropriations have curtailed development of centers.

I. We recommend the number of day activity centers be expanded and that funds be appropriated in the next biennium in the amount of \$2,500,000. (Continued)

The Daytime Activity Center program has been an important factor in reduced demand for institutional care. Not only is it better to allow a child to remain in the community, but centers save the state institutional costs.

The cost for institutionalization runs something like \$6.36 a day while daytime activity center programs cost \$1.37 per day.

II. Amend the Daytime Activity Center Law.

Lift the \$.25 per capita limit on state support since less populous counties are limited in the amount of support they are eligible to receive.

Rent and amortization should be included as a matching item from the state. Elements of the present law handicap program development and funding.

COST OF CARE REIMBURSEMENT BILL

I. We recommend that the state reimburse counties for care of the retarded under 18 years of age, in licensed community residential facilities at the same rate as if they were placed in a state institution.

Development of a significant number of residential facilities is dependent upon a reliable and continuing source of operating funds.

Community facilities can be constructed at no cost to the state, either for original construction, maintenance or repairs, if there is an adequate source of operating funds.

Retarded persons could be placed in the facility best suited to their needs.

The county and family would not be burdened with total cost.

When the child goes to an institution, the state pays the full cost with the exception of \$10 or 10% per month.

Institutionalization is many times the only answer, not the best one.

II. Cost of Care calls for program standards and improved licensing procedures for residential facilities serving the retarded.

The state should be concerned that community residential facilities provide more than custodial care. The state should insure that good treatment and training programs be available to insure that the retarded person develops to his maximum potential.

Three, and sometimes four, separate governmental agencies license residential facilities.

Licensing standards for residential facilities in the state of Minnesota have an overwhelming concern for the physical facilities to the exclusion of developmental program.

Standards and licensing for retarded citizens should be under a single governmental agency, which is knowledgeable in the field of mental retardation.

VOCATIONAL REHABILITATION

I. Increased Field Workers for the Division of Vocational Rehabilitation.

Figures show that a caseload for a counsellor should not exceed 100 since larger caseloads make rehabilitation less likely.

22, 000 potential clients could be served by the Division if more counsellors were available.

2,213 persons whose average age was 25 were rehabilitated last year which represents a saving of \$428,440, 000 over the lifetime of an individual to the State of Minnesota. The saving is determined by monies the person will have earned over a lifetime and the amount of money saved because they were neither institutionalized nor on welfare rolls.

The foregoing figure represents more than the total appropriation asked for in the past 20 years.

II. <u>Increased Number of Sheltered Workshops.</u>

Sheltered workshops serve retardates who, after suitable training, can be placed in private business and industry.

Sheltered workshops serve retardates who will probably always need supervision in a more-or-less sheltered situation but who can earn at a nearly supporting level. Sheltered workshops serve retardates who are productive but at a marginal level and only in a very supportive surrounding.

An estimated 2,200 work stations, just for the retarded only, are needed in Minnesota. Those habilitated will more than pay for the increased appropriation needed to expand the program.

Opportunity Workshop in Richfield has habilitated 200 people in five years, adding \$40,288,000 in lifetime potential savings to the state.

III. Appropriations should be sufficient for this Division so that federal monies will not be lost.

Many of the programs of Vocational Rehabilitation call for matching federal funds, Over 3 million dollars was lost by the State of Minnesota last year because the legislature failed to appropriate enough money in order for the state to receive these federal funds.

DIVISION OF MENTAL RETARDATION

I. There is a need for a staff of highly qualified experts to deal with this large and complicated problem.

Work of the Mental Retardation Planning Council has clarified many of the complicated problems and aspects of mental retardation.

Years of observation, study, and experience show that the programs for the retarded are not developing adequately.

The mentally retarded citizens of Minnesota need a strong, adequately staffed, permanent placed governmental agency within the executive branch to represent them and the coordination of services for their welfare.