THE CASE AGAINST CLOSING THE STATE'S REGIONAL TREATMENT CENTERS

by

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MINNESOTA CHAPTER CONGRESS OF ADVOCATES

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PORTION OF STATEMENT

OF MINNESOTA

CHAPTER

CONGRESS OF ADVOCATES FOR THE RETARDED, INC. (MN CAR)

INTRODUCTION

My name is Mel Heckt, I am President of MN CAR, a Minneapolis lawyer and father of Janice, age 36, whose home for the past 30 years has been the Faribault Regional Center. Jan is severely retarded, has psychomotor and grand mal seizures, severe scoliosis and severe behavior problems, all of which are being expertly treated by FRC.

Jan lives with 12 other women in a separate living unit which has a kitchen, dining room, living room, bedrooms and bath; she works part-time, goes to DAC, receives physical therapy, psychological counseling, nursing care, medical and dental care and drug monitoring by experienced and highly trained experts. She frequently goes downtown for meals, treats, bowling and church. Every waitress at Wimpy's knows and likes Jan; they know she will order chicken and cherry pie alamode. Some of her direct care staff have been with her since she arrived at Faribault.

From 1953-1985 I have been active in the ARC movement. In the past, I have served as president of Minneapolis ARC, Minnesota ARC, Regional Vice President and Secretary of NARC and as a member of the President's Committee on Mental Retardation. I have advocated for almost every community service in place today and for improvements in our State's Regional Treatment Centers. I currently serve on the Faribault Regional Center Advisory Board, and the Laura Baker School and Mount Olivet Rolling Acres Board of Directors.

MN CAR is a non-profit corporation and a member unit of CAR, a national organization consisting of State Chapters whose members are primarily parents, relatives and friends of citizens who are mentally retarded and who reside in State owned and operated Regional Treatment Centers. Some of our members have relatives residing in community institutions which are defined as residential facilities having more than 15 residents.

MN CAR has 153 members and a board of directors consisting of at least one parent or relative member from each Regional Treatment Center area.

MN CAR'S purpose is to defend, promote and enhance the interests of people with mental retardation; to advocate that they

receive quality care, education, treatment and training in the State of Minnesota. We are dedicated to securing quality care in Regional Treatment Centers, Community Intermediate Care Facilities and in other community residential facilities large and small. We believe there is no single mode or series that best meets the needs of all people who are mentally retarded. We support a system of choice and an important role as parents and guardians in the decision making process when determining where the needs of our relatives can best be met.

The ARC and MN ASH want to close the RTCs to all people who are mentally retarded. MN CAR wants to improve and prevent closure of RTCs in order that those whose needs can best be met in or those who have no alternative which can meet their needs for life, liberty, safety, care and treatment will not be denied admission to nor be dumped out of RTCs that meet their individual needs into waivered services community houses for one to four residents which waive services, do not meet their needs and endanger their lives, health, safety and liberty. MN CAR also wants to protect those profoundly and severely retarded and physically disabled and behaviorally affected RTC residents who have no parents or relatives living or able to fight against such dumping.

I.

Regional Treatment Centers must be preserved, maintained and improved to provide care, treatment and needed services for those persons who are mentally retarded and irrespective of age who:

A. Will receive more appropriate and higher quality medical, dental, psychiatric, psychological and nursing care and treatment in the RTC than in their community.

B. Need protection from danger, injury, or sexual molestation when that protection is not available in the community.

C. Have no other alternative in their communities because their communities are located in sparsely populated areas of Minnesota which do not and can not have availably necessary professional personnel and services.

D. Who have lived in their RTC homes for many years and prefer to live with their friends and peers and associate with their RTC staff.

E. Who benefit from living in an RTC located close to their parents and/or relatives and therefore must live in an RTC because of unavailable programs or lack of quality programs within their communities.

F. Although teenagers, cannot live at home with their parents, and who, because of their disabilities cannot live in their communities but with short term or temporary care and treatment at a RTC could be returned to their communities.

G. Need expert respite care and treatment not available in their communities.

H. Need expert diagnostic and programmatic evaluation not available in their communities.

I. Are demitted from a community residential facility and have no appropriate placement available in their community.

J. Are elderly and need nursing care by persons experienced and well trained in caring for persons who are mentally retarded.

K. Have severe behavioral or mental illness problems which could be treated expertly at a RTC thereby enabling some of them to return to their communities.

L. Have severe hearing or sight problems which prevent them from being able to receive education, treatment and habilitation in their own communities.

M. Have chemical dependency problems and need expert treatment not available in their communities.

N. Have criminal or sex offender problems and need correctional and expert treatment not available in their communities.

O. Have rehabilitation needs the services for which are not available in their communities.

II.

Regional Treatment Center's small group homes should:

A. Be able to utilize the expert and experienced professional and non-professional staff of the RTC and not be prevented from doing so by rules or regulations.

B. Be able to easily return a resident to the RTC without a court recommitment proceeding, if the person does not fit in well with the other residents, or is not able to receive necessary services and protection in the small group home or is most unhappy with the transfer to the group home.

C. Be increased in numbers not only for those few from the RTCs who in fact could be appropriately placed therein but those from the community who are on waiting lists for residential services.

III.

Our Thanks to Minnesota

Minnesota has some of the best RTCs in the nation. Over the years Minnesota has substantially improved its RTCs. Increased staffing and training has vastly improved the RTCs programmatic services; over crowding has been substantially eliminated; the living environment has been substantially improved by renovation of the buildings which now have a maximum of 15 residents per separate residential living unit. Some have 10 residents per unit. It has some of the most knowledgeable and experienced professional and direct care staff to be found and 90 to 95 per cent of the parents, guardians and relatives of the RTC residents who are mentally retarded are most grateful for the substantial progress that Minnesota has made. We have in the past appreciated the stability of and progressive changes made in our State owned and operated RTCs.

IV.

Our Concerns with the Present Minnesota State RTC System

A. It unreasonably restricts admission of people who are mentally retarded to RTCs.

1. It denies admission to or limits the admission to a short stay for some teenagers and others under 18 years of age whose needs can best be met or only be met in a RTC.

Although babies and little children should be encouraged to live with their families or foster families, some teenager's needs can best be served in an RTC.

2. It now has a County Case Manager System with almost unlimited power to place people in small waivered service homes when the individual needs the care and treatment of an RTC.

a. Each county is assigned a quota of waivered service dollars. If it doesn't spend these dollars, it loses them. This type of funding which takes dollars away from RTCs and community ICFMR facilities and transfers them to waivered services homes is as discriminatory as our past system which erroneously gave a financial incentive to counties to place people in State RTCs.

b. Many case managers are inexperienced and ill trained or untrained to know the needs of profoundly and severely retarded persons.

c. Many case managers are under severe pressure from the State and private providers to fill the small

waivered service facility with people; otherwise the owner of the home will go broke or discontinue the service and therefore, the case manager may place people therein even though they need the care and treatment provided by a RTC and can not receive the quality of care in the small home.

3. It has a Division of Developmental Disability and a screening team procedure that discourages and restricts admission to RTCs for those who could receive better care and treatment in a RTC than in a waivered service facility or small group home.

4. It has a Court Commitment System designed for mentally ill and chemically dependent people of normal intelligence and not for people who are profoundly or severely mentally retarded. This Court Commitment System does not provide for voluntary admission of such people by a parent or guardian to a RTC. It also discourages some parents and relatives from becoming involved with a Court procedure which pits them on the side of favoring admission and a court appointed lawyer who receives fees for preventing admission even though his client cannot communicate his or her wishes and is incompetent to make a choice.

5. It restricts by statute the development of new ICFMRs to six beds or less.

6. It decertifies beds at RTCs and thereby restricts new admissions. It unreasonably limits staffing at RTCs thereby requiring the closure of buildings rather than using the buildings for fewer residents per living unit which would benefit the mentally ill - mentally retarded population.

B. It unreasonably discharges people who are mentally retarded from our RTCs.

1. It provides each county with a quota of discharges from RTCs, a quota of waivered service funding and a county case manger with almost unlimited power to implement the quota discharges.

a. Even though the resident or parent or relative objects to such discharge.

b. Even though the RTC resident may have no friends or relatives presently living in the county of financial responsibility or of transfer and be forced to leave his RTC friends.

c. Even though the transfer may send the person a much farther distances from his parents or relatives.

d. Even though the transfer may place the person in imminent danger to his health or life.

e. Even though the Welch court decree of quota discharges has been met.

f. And of most importance, even though his need can better be met at the RTC than in the small house.

2. It provides free legal aid to those few who now want to be discharged but denies free legal aid to those many who want to stay in their RTC home.

3. It applies pressure upon RTC staff to not object to a discharge, pays little attention to RTC staff when it does object and pays great attention to the opinion of the county case manager, county guardian and waivered service provider who favor the discharge.

4. It forces the residents, contrary to their or their parents, relatives or guardian wishes, to be discharged from RTCs to waivered service homes or to community ICFMR facilities, or to be discharged from community ICFMR facilities to semi-independent living or supervised living arrangements and at the same time denies people in the community from necessary admissions to the community ICFMR, SILS, SLAs and waivered service homes.

5. It discharges people from RTCs which are well monitored, have quality assurance programs into small waivered service homes and small group homes which can not be effectively monitored, do not have quality assurance programs and, in many instances, do not have to meet State standards.

6. It discharges people to small homes when the individual needs more protection, supervision, safety precautions and quality of care than the staff employed by the small home is able to administer. Thus some of those so discharged have been killed by automobiles in crossing city streets, have died from drinking salt water, have been over-medicated to control behavior, have been raped or beaten, have died from falling downstairs while having a seizure

C. It is knowingly or unknowingly proceeding rapidly toward the destruction of all RTC programs for people who are mentally retarded and thereby ignoring the wishes of 90 to 95 per cent of the parents, relatives and guardians of such persons and denying them the right to choose the RTC as the best and least restrictive environment for their loved ones.

1. It (DHS) has endorsed the Chaffee bill S.1673. Although the Chaffee Bill has some good sections which enable parents to exercise freedom of choice, its bad features, if our interpretation is correct, cry out for its defeat:

a. States must restrict admissions to RTCs and community institutions (those having more than 15 residents or a cluster of two to three buildings have no more than eight residents each).

b. It freezes federal Medicaid funding of all RTCs and Community ICFMRs institutions. (In Minnesota there are 4000 people who are mentally retarded who live in RTCs and community institutions.)

c. It requires that within 18 months (and annually thereafter) all residents of community and state institutions have their service needs determined in order that they can be transferred to a family home, foster family home or community living facility (3 times average family size in the area.)

d. Then it requires that any individual so determined to be in need of alternative residential placement shall be transferred from such institution no later than 40 months after his service needs have been determined and all others must be transferred within the next five years. See (d) State Implementation Strategy et seq. pay S11960 of Congressional Record 9/10/87.

e. It also erroneously concludes that all receiving habilitation services will acquire skills necessary to achieve independence, productivity and integration and to live successfully in home and community based settings.

2. It has a Court Commitment law which was designed for mentally ill and chemically dependent people who express an intent not to be institutionalized and treated. It was not designed for profoundly and severely retarded people who are and have been adjudged incompetent to make such a decision. Court commitment is now required in order to secure care and treatment in an RTC. Court Commitment is now not required in order to secure care and treatment in a foster home, waivered service home or small or large community ICFMR facility. Neither should require court commitment unless the individual or his parent, relative or guardian objects.

3. It has changed the Public Guardianship law and its administration. In the past, the county social worker and the parent or relative were partners with deference being given to the parents wishes with respect to placement. Now,, DHS, the screening team and the county case manager can make

the decision and ignore the parents', relatives' or guardians' wishes thereby leaving them the option of taking an appeal at their own expense.

4. It has adopted a waivered services funding law which is a positive and good concept for parents who want to keep their children at home or in a foster home or in a non-ICFMR community living facility, but it unfortunately was designed in such a way that people residing in RTCs and community ICFMRs must be discharged in order to find dollars to expend for waivered services. This ignored our successful history of developing community services for people who are mentally retarded. Success came from starting small and expanding the service every two years in order to meet the need. Now we are pitting service against service and have turned the power over to well intentioned but sometimes misguided professionals to make dictatorial decisions resulting in dumping which always happens with quota funding and quota discharging.

5. Thus we are concerned (a) that the present population of our community and state institutions will be dumped, have their lives endangered, their bodies and minds injured and will receive a lesser quality of care from less skilled and less experienced care givers; (b) that the Chaffee bill will be a budget buster which will boomerang upon the entire mentally retarded population (Congressman Frenzel advised that the Congressional budget office and DHS are one billion dollars apart on its costs); (c) that Minnesota will destroy the excellent community and state institutions that have been developed, remodeled and made home like at a cost of many millions of dollars; (d) that freedom of choice will be denied and all will be forced into the small group home; (e) that under either the Chaffee or MN ASH proposal - 4000 people would have to be transferred to 500 to 2000 new homes which will be impossible to monitor and provide quality assurance. If it were possible to adequately monitor, the monitoring bureaucracy would sap needed tax dollars from the provisions of services to those in need.

V.

Recommendations of MN CAR:

A. All of Minnesota's Regional Treatment Centers must be preserved, maintained, improved, designed and adequately funded to provide care, treatment and individualized needed services for those persons who are mentally retarded and are included within the 15 groupings of people mentioned in Paragraph I.

B. Minnesota's State Owned and Operated Group Homes should be maintained and expanded as set forth in Paragraph II. Any legislative or administrative barriers which may prevent the

person from returning to the RTC if his or her needs can best be met therein should be removed.

C. Minnesota should change the present policy of restricting admissions to RTC's of people who are mentally retarded and whose needs can best be met at a RTC.

1. Our Public and Private Guardianship and Conservatorship Statutes and our Civil Commitment Statute should be amended in order that adults and some children could be voluntarily admitted to RTC's by their parents, guardians, conservators or relatives without the necessity of a court commitment in the same way they can now be admitted to a community residential facility without court commitment. If the person objects thereto, he should have the right to a commitment hearing. Thus a separate commitment statute should be proposed, the present one is obviously not designed for profoundly, severely, or even most moderately retarded persons.

2. The County Case Manager and Waivered Services Funding Systems should be changed by amending statutes and rule to eliminate the present practice of assigning a quota of Waivered Service dollars to each county which must be spent or lost and which thereby results in either the creation of Waivered Services homes not needed, or the assignment of people to said homes when their needs can best be met at a RTC or community ICFMR institution and in the loss of needed dollars for the RTC. This Waivered Service funding system is as deplorable as giving counties a financial incentive to place people in a RTC as opposed to a community placement. The practice of placing a person in a Waivered Service home to keep the owner from going broke or discontinuing service cannot help but result in dumping.

3. Minnesota Screening Team proceedings should either be eliminated or amended:

a. to require a screening team decision before anyone could be admitted to SILS, SLAS, Waivered Services Homes, community ICFMR group homes or community ICFMR institutions as well as for admissions to an RTC.

b. to require that the screening team members be free from bias or prejudice in favor of or against the RTC facilities and programs.

c. to require that a medical doctor experienced in treating mentally retarded persons be a part of the screening team with veto power; is not, that his opinion be given a preponderance of weight in deciding

placement of a medically fragile mentally retarded person.

d. to require that the opinion of the parent, guardian or relative be given a preponderance of weight in the decision making process and, in fact, MN CAR prefers the old system of the county social worker and parent making the decision. Today we believe there is a greater danger that a bad placement will be made in a community living facility than in a RTC but still believe, with few exceptions, parents, or relatives or guardians should make the decision.

4. Minnesota's present practice of decertifying beds at RTC's should be reviewed to eliminate unreasonable restriction of admissions. Rather, increased staffing should be required especially for mentally ill-mentally retarded persons in order that buildings would be used and not closed to provide fewer people per living unit.

D. Minnesota should change its present policy of de-institutionalizing and discharging RTC residents who are mentally retarded and whose needs can best me met in a RTC.

1. Our Minnesota Administrative Practice, Rules and Statutes which authorize the assignment to counties of quota discharges, quota waivered services funding and almost unlimited power in the county case manager to implement discharges from RTC's should be rescinded and changed.

2. Waivered Services Funding should be used for diversion from RTCs of those persons who do not need the 24 hour care of a Community ICFMR or RTC and whose parents, relatives or guardians request same. It should also be used for discharge purposes only for those persons whose parents, relatives or guardians request same.

3. Waivered Services Funding and Title 19 funding should not be used for discharging RTC residents to a waivered services home and program or to a community ICFMR Group Home or Institution, if the RTC resident or his or her parents, relatives or guardians object to the proposed discharge even though the RTC resident is under State Guardianship or State Conservatorship.

4. Waivered Services Funding and Title 19 funding should not be used for discharging RTC residents under State Guardianship who have no living or interested parents available, if the RTC resident objects to the discharge. If the RTC resident is unable or incompetent to object or agree to a proposed discharge, and if either the ombudsman or RTC interdisciplinary team object to same, the person shall not be discharged.

5. If the recommendations set fort in 1. through 4. should not be accepted then the appeal procedure from the county case manager's screening team's proposed decision to discharge must be strengthened.

a. Since free legal services are provided to a person requesting a discharge, free legal services should be provided to the RTC person or to his or her parents, relatives, or guardians who object to such a proposed discharge. These legal services should be provided through the administrative and district and Supreme Court appellate levels.

b. Such legal services should be provided to the ombudsman or to the RTC Interdisciplinary Team when they believe that the proposed discharge will not provide better or equal care and treatment or may endanger the person's life, health and safety for the RTC resident who does not have any parents living or available.

c. DHS and its divisions should refrain from applying pressure upon RTC staff to not object to a discharge; rather RTC staff should be encouraged to object and appeal a proposed discharge if it concludes that the person would receive a lesser quality of care or that his needs will not be met in the community facility.

d. The county case manager screening team should not discharge a medically fragile RTC residents over the objection of the experienced RTC medical director.

e. Minnesota Rules and Statutes should clearly provide that any discharged RTC resident may return to the RTC at any time within two years from date or discharge without having to be recommitted by a Court or be rescreened. The current probationary or proposed discharge period is too short a period of time.

f. Another appellate procedure which should be given study, is the possibility of objections to discharge being heard by the committing court. If the court must commit a person before the person can be admitted to a RTC, it would seem logical that it should hear all objections before ordering a discharge.

E. The Minnesota Department of Human Services should rescind its endorsement of the Chaffee bill S. 1673 unless it has decided that all RTC's and all 50+ ICFMR Institutions for persons who are mentally retarded should be discontinued. Unless our interpretation of the present Chaffee bill is incorrect we believe such destruction must follow if the Chaffee Bill as

3. New RTC programs be designed and implemented.

4. Voluntary admission as opposed to court commitment be encouraged and that court commitment be used only if the person, : or in the case of the mentally retarded person who is unable or incompetent to express his intent, his parent, relative or guardian objects to such commitment.

5. MNCAR's other recommendations herein be studied and implemented.

6. Quality care and treatment which meets the needs of each individual and not the size of the facility should be the goal.

7. The many excellent ICFMR community institutions should not be depopulated and destroyed.

8. Additional funding be provided for the funding of a variety of community living options rather than a single two to a house option.

We sincerely hope that we and our loved ones will not have to live with the mistakes of the social experimenter experts.

A PROPOSAL TO: By: Dean Thomas

The State of Minnesota Department of
Human Services Comprehensive Regional
Training Centers Organization Proposal

THE "EXCEPTIONAL" CARE PLAN

Concept: A state health care plan structured from the extension of Regional Centers to full service capability that guarantees superior care, treatment, training and living quality assurance for the mentally ill, mentally retarded, chemically dependent, developmentally disabled, elderly and homeless.

Tenets:

I. Organizational structuring based on sound principals of financial feasibility that assures the reality, and maintenance, of superior care and living quality.

Advantages

1. Leadership from an existing nucleus of Regional Center facilities and organization.
2. Supervision assurance with methods now in place to be enhanced.
3. Quality assurance guarantees through organizational development.
4. Financial feasibility for legislative understanding, support, and reality.
5. Timely evaluation now on line developed through improved process of management.
6. Built in basis for innovation and improvement.

II. Development of cost efficiencies of tax dollars through utilization of present exceptional state resource sharing.

1. Efficiency of combining inter dependent operations for Regional Centers, ICFMR's, community placement units state and private.
2. Existing personnel utilization.
3. State land, outstanding buildings excellent environments and locations with hospital facilities.
4. Available treatment facilities availability for regional populations.
5. University of Minnesota involvement through state organization.

III. Improved organization for continued development of technology, training and facility improvement on a short and long term plan without commitment.

IV. Capitalize on today's solid base of cost information to provide financial stability to short and long term planning. Rather than, the undetermined basis of "social experimentation" which could seriously damage the ability of the State to serve financially.

V. Adapt operational plan to encourage the programming, supervision and growth of community living and private enterprise, in all fields, where that service offers the same high standards of care and supervision, as a supplement to State services.

VI. Maintain Regional Centers, as Regional Care Centers, to protect the present distressed population of severely and profoundly retarded population and other present clients where "social experimentation" is both unadvised and life threatening.

VII. Revise the commitment regulations to permit both short term and long term care, without the "serious threat" of only long term commitments. Operate Regional Centers on the same commitment basis as community living or private care facilities.

VIII. Protect the rights of Minnesota's people to have choice, and voice in the system of care through clients, friends, parents, guardians and organizations which offer important evaluation and critique.

IX. Organizational structure that works toward Federal compliance of care and qualification within the state guidelines of exceptional care.

X. A responsible system of care statewide that protects clients as well as the communities of Minnesota.

ORGANIZATIONAL FUNCTION

1. Under the leadership of an appointed Board of Regents the State Department of Human Welfare would redesign the care systems for the mentally ill, mentally retarded, developmentally disabled, chemically dependent, elderly and homeless. The new design would update its present rules to include "today's state of the art", but provide for an ongoing department of developmental research that would continually upgrade methods, standards and care.

2. The basic structure of practice would be seven "Exceptional Care Centers" to serve Minnesota regional areas of service.

3. The organizational structure to manage those regions would be a horizontal style of "hands on management". Decentralized to do the job effectively in both the private and state facilities.

4. Size would not be a criteria, but quality of service would be the fundamental concept of measurement, as would cost of care.

5. "Exceptional Care Centers" would form the nucleus of each Region, but operating under a format of regulations to include the operation of community units as well as continued care at the Regional Training Center facility.

6. It would be axiomatic that whatever care facility was operating, public or private, all would have to maintain qualification based on the revised standards of care created by the Board of Regents.

7. The State Commitment laws would be modified, and care would be administered on an out-patient, or in-patient system of short or long term treatment as required, with the consent of the parent or guardian.

RATIONALE SUPPORTING "EXCEPTIONAL" CARE PLAN

1. The ability to satisfy the "serious concern" for today's residents of the Regional Training Centers who have strongly presented their conviction for the Regional Center as their choice for placement.

2. These Regional Center advocate represents a major portion of today's Regional Center population. They are intelligent, caring people, who are as convinced they are right, as the opposition. These people know the Centers far better than any collective group. Their base is not narrow, and their understanding of their loved ones problem and care, can seldom be disputed. The point most often missed by the "outside advocates" is that the various programs of the profound and severely retarded population must be individually tailored, and professionally executed. Such care is not within the financial capability or expertise of the community placement recommendation.

3. If the state of Minnesota means freedom of choice then the Regional Center's population cannot be denied as the ARC and MNASH demand.

4. As all negotiators agree, any system must have appropriate care, but they must also agree, there have to be programs that match individual need. This requires a resource of talent that is far above custodial care levels. It requires a resource of people who know, and are being trained, in the "state of the art". Community placement has no ability to match this demand on an ongoing basis for 2,000 units needed to house the "exceptional" persons.

5. Example: For a program of one on one care, to prevent employee "burn-out", there must be at least ten people trained in the skill of operating that program. An impossible task for a small community facility that could have three "one on one" requirements.

6. It is a misconception to visualize the future of Regional Centers as they exist today. Although they are fully adequate today, it is not the present we are really dealing with, it is tomorrow. Under the "Exceptional" Care Plan that future is assured with its built-in provision for growth and development. Again, how would that be possible with a community of two thousand franchises of varying competence to collectively manage research, development, training supervision and evaluation.

7. The general assumption of "big" is "bad" is a dangerous position when you measure the complexity of the problem we are negotiating.

8. The "Exceptional Care Plan" embraces the community living concept, but also structures organizational capability to sustain it.

9. Most of the Regional Centers criticism is anachronistic, meaning years ago, when the "institution" was insensitive to its clients. The Patricia Welch case was built on "years ago" problems which perhaps did exist, but not today. The MNCAR membership is living proof of the satisfaction of regional center care.

10. Based on today's performance of community placement it would be disastrous for the state of Minnesota to close its regional centers. Today's headlines of community living neglect and public criticism are the early warnings of a system that simply won't work. The results of that failure are tragic.

MINNESOTA CHAPTER CONGRESS OF
ADVOCATES FOR THE RETARDED, INC.

We as parents and friends of people with mental retardation have become a Minnesota Chapter of Congress of Advocates for the Mentally Retarded, Inc. with the purpose "to defend, promote and enhance the interests of people with mental retardation and to provide them quality care and training in the state of Minnesota". We are dedicated to securing quality care in Regional Treatment Centers, Intermediate Care Facilities and in the community, as there is no single mode of service that best meets the needs of all people with mental retardation. We support a system of choice as well as a voice by parents and guardians in decision making when determining where the needs of those, for whom we are responsible, can best be met.

May we carefully point out we are "for" all qualified methods of care that support our statement of purpose - large or small, private or state, community or regional training center. The MNCAR membership positively proves Regional Training Centers strongly qualify and it is now time that this fact gets recognized. MNCAR stands steadfastly opposed to the distorted position of those who unequivocally recommend Regional Centers closure for those they do not represent, know, or seem to care about.

Our plan of presentation here is to present the "Exceptional" Care Plan. An innovative process that can embrace "all" present systems of care. Its format, a state organizational structure that develops, and maintains, the highest level of standards for each qualified unit on an equal and demanding basis.

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Robert W. Johnson
Stephen D. Johnson
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June 30, 1988

Sandra S. Gardebring, Commissioner
Department of Human Services
Centennial Building St. Paul, MN
55155

In Re: RTC Negotiating Committee

Dear Ms. Gardebring:

In order for you to identify which Bob Johnson is the author of this letter, I would simply indicate that I am the former Anoka County Attorney.

My interest in this entire effort stems, first, from the fact that our son Sandy has been a resident of Cambridge State Hospital for over thirty years. Secondly, as County Attorney I had the responsibility and opportunity to observe community based foster homes, halfway houses and smaller types of quasi-treatment facilities. Those observations give me substantial concern about the ability to supervise and discipline the quality of care that everyone wants for the people using the various care facilities. I've seen both the good and the bad. Some of the good was really outstanding. Obviously, I would see more of the bad because I'd be called upon to prosecute in various situations that would flow from having inferior facilities, or, more particularly, the people involved were either not trained or psychologically not competent to handle the responsibilities they were given.

I have reviewed the information and minutes of meetings forwarded by The Conservation Foundation. I attended the meeting on June 24, and I must say I am very impressed with the effort you have undertaken to determine what the future should be for regional treatment centers. The facilitators are very competent, know what they're doing and where they're headed. You are to be complimented on organizing this effort. I was impressed with the effort made by the CEO's of the various institutions. It's impressive to observe and absorb the immensity of the investment the State has in the different institutions. It occurred to me that the public would be well served to know what kind of investment we as a society make for the disadvantaged people, whether they're mentally ill, retarded, chronic alcoholic or whatever. The effort was very demonstrative.

I would direct my concern in this letter to the effort that is being made to de-institutionalize all of the mentally retarded. I should at the outset indicate that I have very grave concern about that effort. I participated very actively in the early stages with. RISE, Incorporated. I handled the incorporation, and made the major effort to get the funding through the County Board. I am very familiar and aware of the wonderful things they are doing, and I applaud that effort. I also recognize at the outset that there are many retarded people who were in institutions in the past who are now out in society and by all observations would appear to be happier in their present surroundings than they were institutionalized. I also can attest to the fact that as County Attorney I had several very unfortunate situations where people took advantage of the retarded as they were attempting to function in society. That is the down side when their circumstances are not properly handled.

There should be agreement by all parties that we want the best possible care for the mentally retarded. We all recognize that these people function at different levels of competence. They have emotional and physical handicaps which require different attention and care. We would all prefer they reside in an environment which will maximize their opportunity to live their lives in happiness and self fulfillment.

We will differ on our ability as a society to provide these laudable goals. We should identify the demands for specialized services that are required. Some obvious ones are as follows:

1. Specialized Medical Care

   A. Recognizing the individual's often inability to communicate physical problems.

   B. The physical condition of many result in a vulnerability to various diseases and peculiar physical problems.

2. Hygiene

   A. Cleanliness

   B. Bodily functions

3. Emotional Needs

   A. Psychological problems

B. Communication

C. Understanding needs, patience, ability to maximize their functioning level

4. Educational Opportunities

A. Specialized approach and individual approach to maximize their educational advancement

5. Recognizing Levels of Individual's Social Skills

A. The ability to maximize their opportunity for self fulfillment, peer group interaction and ultimately to find happiness in their lifetime.

I believe everyone would have to agree:

1. Centralization affords the best opportunity to supervise and insure quality care.

2. Community based small care facilities cannot be supervised or disciplined with the same thoroughness as a regional treatment center.

3. Society's experience with foster homes, halfway houses and other community based facilities has in many cases resulted in tragedy. Obviously in many instances it has resulted in some real success.

4. Some of the retarded function very well in community based facilities while others require specialized care that would be difficult at the community level.

In talking to the social workers who supervise the placement of retarded children, they affirm to me that there are very few doctors or medical clinics who really know how to provide medical service for the mentally retarded. Obviously, as we de-institutionalize further than has presently been accomplished, there would be a reduction in the centralized medical care that would be available from those who, certainly by their experience and training, would be able to provide more adequate care to the peculiar types of problems. The inability that the patients have to communicate their problems to the doctor speaks to the need to maintain the regional treatment centers and the centralized capacity for medical care.

One of the efforts occurring both at the national and state levels that I have not heard being addressed in this deinstitutionalization effort is the taxing of non profit corporations. As you know, both the national and state level are making the distinction in their effort between the philanthropic and what they identify as the commercial non profit organizations. A concern should be that if the commercial non profit includes the delivery of services that many of our halfway houses and community based facilities provide, then obviously that taxing would create an additional cost. It's interesting to me to know that some of the strong advocates for this taxing of non profit organizations base their efforts on the belief that services to the handicapped and the mentally retarded, mentally ill and so on should be handled by government and not by private enterprise. When these advocates are asked why do they wish to create this round-robin facade of taxing a non profit organization who then in turn must up their rates in order to recoup that cost, which will then go to the county or the state and generate more need for taxes to cover the additional cost - you really are taking money out of one pocket and putting it into another. When confronted with this argument, they simply say they should go out of business and the government can provide those services more efficiently, more equally and supervise them more adequately than if they are fragmented.

I serve on a couple of Boards of Directors, one that deals with delivery of services. Two concerns have now surfaced. First, as time goes on and the State begins to recognize the need for additional training and services at the community based facilities, they are being required to have additional training for personnel and services to meet the needs of their clients. The reason for mentioning that, of course, is that this relatively new effort, if measured by its present cost of delivery of services, would be a misreading because in the long run, as more and more demands are made, obviously the cost would increase. The second concern that these non profit organizations have is the liability factor. Anoka County has the problem of a foster home and the County being sued for injury to a client which the plaintiffs claim occurred because of lack of training of the foster parents. That is in litigation, and the effort on the part of the County to get dismissed, as you well know, failed. So the County has been held in as a party. I mention that only to indicate that, as the history develops on the injuries that are going to occur to the various clients in these facilities, you surely are going to have lawsuits that will force up the cost of insurance which is already very high. As a matter of fact, I would not be surprised if we would soon reach the point that governments were in just a matter of three or four years ago, where the insurance just was not available. If you

think about it a little bit, the private individual is caring for a severely retarded child who happens to get injured, and the parents of that child then bring a lawsuit - they're going to be examining the quality of the training of the individuals who were supervising; was there enough supervision; did they have enough training; what is the basis for allowing the particular individual or individuals to have responsibility for the care of these severely handicapped and retarded people. If that insurance problem surfaces, and I am sure it will given past history, then we're going to be in the very difficult situation of re-institutionalizing these severely retarded.

It occurs to me that the commitment process should be examined. There are an endless number of situations that surface in society where placement of an individual is necessary for a period of time, from getting them squared around on their medication or to relieve tensions or problems at home to a multitude of reasons why a temporary type of placement could alleviate a situation. I mention that only in a simplistic fashion, but I believe it is being examined much more thoroughly. That type of proposition sounds very attractive to me. Obviously, the regional treatment center would have to maintain the capacity to handle that type of temporary, as well as more permanent care.

On a personal basis, our son Sandy is very severely retarded. We have lived with some rather difficult situations at times. There was a period about fifteen, twenty years ago when they attempted at Cambridge Hospital to impose much more stringent training methods and techniques on Sandy as well as the other residents. Some responded well to it. Sandy on the other hand regressed to the point where he was falling. We had to get headgear for him. He regressed from his already minimal capacity. Sandy does not recognize us. He does not speak. His capacity is measured at something under one year of age. He has club feet. He's physically handicapped, and the care that he requires is constant and in the hospital once or twice a year, usually on an emergency basis. I'm absolutely convinced that, if Sandy were in a lesser quality facility, he would not be with us today. I realize that some parents have had trouble at Cambridge. We parents are sometimes very, very demanding and unreasonable, and I suppose at some time the expectation of a parent has not been met. Sometimes there has been a mis-diagnosis, and those things do happen. However, our experience over thirty years has been that the Cambridge staff are very caring. They have given Sandy excellent care, and Charlotte and I would be very upset Sandy had to be moved out of that caring type of facility into a community based facility. A community based facility, if you happen to get to the right one, might be fine, but he has so many problems, and emergencies arise, and he requires constant care.

I'm afraid it's been a long, rambling letter, but it's an effort on my part to respectfully urge that you not try to de-institutionalize everyone and that you maintain regional treatment center capacity for the mentally retarded, as well as the mentally ill and other problems that have to be dealt with. Be wary of the broad brush conclusion that deinstitutionalization is per se going to make all of the various patients happier. That just would not be the case. We parents tend to impose our desires as a conclusion of what would make our children happier. It is very difficult for us to really conclude for these people who are so handicapped what kind of environment would make them happiest, and that after all should be our goal. I submit that back in those early days, when Charlotte and I . spent a good deal of time up there at. Cambridge, the patients, indeed within their own little world up there, were happy. I recognize there are many who have come back into the community, and some are happier, but I submit to you from my experience as County Attorney, some are not. Thank you so much for your patience in reading this. I appreciate your attention.

Respectfully,

Robert W. Johnson

RWJ/jr