ORIGINAL

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State Hospital Study

Town meeting at: 3701 Wayzata Blvd.
Minneapolis, MN

Thereupon, the following proceedings were had before Debra C. Schmidt, RPR, Notary Public in and for the County of Hennepin, State of Minnesota, at 3701 Wayzata Boulevard, Minneapolis, Minnesota, on October 9, 1984, commencing at 7:00 p.m.

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Transcript of Public Testimony;

MR. TAPPER: My name is Harold Tapper. T-a-p-p-e-r. I'm the Executive Director of the Association of Residents for the Retarded in Minnesota. On behalf of the Association

MS. KARLINGS: I want to – if you can't hear, raise your hand so we can be sure that everybody is hearing.

MR. TAPPER: On behalf of my association representing community residential facilities and providers, we have developed a state method that revolves around four issues. We've asked four members of our association to speak to each of those four issues. Those issues and speakers are: First of all the importance of a single system of service will be addressed by Pete Jacobson, residential alternatives. Jean Starles will address the state's proper role on service delivery. Eileen Harris will talk about the state's role on quality assurance. And Walter Baldus will talk about maximizing job opportunities for state hospital employees.

Each of us will not consume more than three minutes, and I will come back at the conclusion of the presentations to use up the balance of my allotted time.

MS. KARLINGS: All right. Very good. Thank you.

MR. TAPPER: I'd like to call on Peter Jacobson.

MR. JACOBSON; Thank you. As you heard my name is Peter Jacobson. We operate a small six to nine bed ICFMR group homes and department training programs. I'd like to talk about

my concerns regarding a single system. We may talk about everybody should play the game by the same rules. Kindly the community based service system functions on the basis of friendly cooperation. Large facilities, small agencies, group organizations, individuals, nonprofit corporations and private corporations all operate under a single set of rules. These rules include licensure, certification, case management, placement and reimbursement. When I build a six-bed group home, the water temperature, the dishwasher, the sprinkler system, the alarm system, size of facility are all set by standards.

Our program standards must meet or exceed the HS regulations. And our level of supervision must meet the safety and maintain safety for all well being of our residential, after all, that's what the bottom line is, our residents. That's why I got a business.

I believe I've provided quality service that goes beyond maintenance and bodies and quality of life. My concern reaching towards the future is that if the state becomes involved in providing community-based services they will not do so under the same set of rules. For example, the current state hospital system has a separate reimbursement system, which allows the state to pay higher wages to its employees. A major factor in keeping state workers — state work from entering the private sector.

If the state becomes a community-based services provider, I

will be competing with the state or the best qualified workers. Will I be able to provide the same I wages and benefits enjoyed by the state workers? Will I be at a disadvantage because the state doesn't have to play the rules the same as I do?

The second area that concerns me is my capacity to provide new and needed services such as Class B ICFMR programs.

My organization as an alternative was selected by a major urban county recently to develop a 32 bed Class B facility serving medically fragile and behaviorally involved individuals.

When we were ready to begin developing this project the state established a moratorium. We couldn't complete the project.

Recently I've heard the state is interested in using Class B development as a mechanism for creating jobs for the state hospital personnel. Will I be able to compete equally with the state in bidding, bedding, operating, owning future community-based services and facilities? Or will the state play by a different set of rules?

in conclusion I would like to say I appreciate the difficulties we, you and I, as a state face in determining what to do about our state hospitals. I operate a 66 bed group home in Cambridge, Minnesota. Our staff lives in the community. Their children attend the public schools. Our residents live there and work there. I know what a devastating effect both economically and spiritually the enclosure of the state hospital

would have not only to the community but our staff and residents.

I also know what a devastating effect the creation of a separate set of rules for the state in providing community services would have on the private sector. I believe we must search together in finding an effective economically viable answer to phasing out the state hospitals. The quality or establishing the same set of rules for all employers from the beginning, I believe, is how we win the game. Thank you.

MS. KARLINGS: Thank you.

MS. STARLES: My name is Jean Starles, S-t-a-r-1-e-s. Historically the State of Minnesota has acted to provide services when the community could not meet the needs of all clients. In the early 1960's the state hospital system served over 6,400 mentally retarded people. In those days there were very few community-based facilities serving under 500 people.

Community alternatives then consisted of private and state nursing homes, foster homes, and less than ten community facilities.

When I was a social worker in the state hospital system in 1967 there was considerable excitement that serving community facilities were developing to service our residents. We felt good about moves that would bring residents closer to their families, that will enable more direct community contact, that would enable people to live with fewer people, sometimes for the first time in their lives.

As that we participate in the beginning of a real movement to in a sense force the community to serve all of its citizens. When this was a time when the community as well as families in some cases branded handicapped people out of sight and the mind.

In the early 1970's enabling legislation supported zoning and regulations and funding, provided the base for a major developmental process in Minnesota. Community-based residential facilities were encouraged to develop, and funding even provided for technical assistance to enable people to get through the complex process of licensing, certification, security funding and so forth.

In my experience as staff on this state technical assistant project, I work with providers and developers as they design specific programs to meet the needs of people living at the state hospitals. More than once we, the developers and I, visited with state hospital employees who described the community needs of the residents they served. We were all excited to see some of those same residents move into a facility within the year or so to look to develop it.

Thus the community residential service sector expanded to exist of more than 334 facilities serving over 5,100 people in more than 70 counties in Minnesota.

Other services such as semi-independent living programs expanded educational programs, development achievement, sheltered workshops, and home family support programs,

professional foster care, and resident care has been developed or expanded to enable the mentally retarded person to live in the community. With this the role of the state hospital service has narrowed. It occurred through good intentions.

For the clients served by both the provider of state and community-based services the State of Minnesota needs to continue in the role of being responsive now and in the future to the growing capacity of the community to provide services, developmentally as a community refines and extending itself still into new service areas. It will have the capacity to meet the complexities of needs of these people still in state hospitals or who may be considered for placement there in the future. Thank you.

MS. HARRIS: I am Eileen Harris. I'm associated with The Outreach Group Homes, which operates seven six-bed intermediate care facilities, and also group homes which operates one six-bed intermediate care facility and some sales programs.

The issue I'd like to address is quality assurance and its implementation. Minnesota was one of the first states to establish a single standard for its program services to the mentally retarded. Rule 34 was written and is implemented to provide a single standard with clear expectations of program performance. The responsibility to assure the delivery of quality care and services is delegated to the State of Minnesota through its departments of health and human services.

Public and private providers have a responsibility to self-impose checks and balances, adherence to single licensing standards and monitoring clients by a third party enhances the delivery of services.

Given that the State Board provides services and monitors its own, the checks and balances are not consistent. Thus a dual standard and a dual system becomes evident. The way in which a system is perceived effects its credibility. For the state to provide services and monitor its own compliance is to me a conflictive interest. The perceived dual standard results in licensing becoming less effective and eventually less enforceable.

I believe the quality assurance needs not be dualistic. The growth of community programs has posed concerns and questions for all of us who seek to provide quality care.

The increased number of alternatives is paralleled by increased problems. Yet also the array of possible solutions.

Monitoring is more complex within the community, and that disturbs network of service itself and physically more difficult to reach. Concepts like quality of life are more difficult to measure. On the other hand, the role of accounting in case management is being strengthened. It plays to each person receiving servicing regardless of who the provider is, public or private.

This is an important requirement for quality assurance in a

decentralized service system. The issues of less restrictive alternatives, quality of life, community integration, economic deficiencies, job security, et cetera, become platforms for this agreement.

These areas can be addressed into such a way to create the standing of the platform of agreement. Programs based on client needs, services that exist and that are to be developed may incur stress and change, but must return to the primary focus, client centerness. Inherent to client centerness is one's right to be a part of the community, defined as a group of people who interact.

Community integration imposes a rhythm of life with continuous and non-biased feedback to individual behaviors and skills. The multiple contacts one experiences within the community further imposes checks and balances on the programs and their effectiveness, what I believe to be a purposeful and independent tool for quality assurance.

The State of Minnesota should consider becoming proactive by considering alternatives in which quality assurance is independent of the provision of the services. The areas of concern can be aired and resolved in such a way that everyone experiences the benefits, clients first, providers second. Creative solutions can provide healthy -environments in which alternatives can prosper and residents can grow. Thank you.

MR. BALDUS: Thank you. My name is Walter Baldus.

I'm with Woodville Management Services out of Austin. We operate a number of residential facilities for the mentally retarded as well as some independent living programs, foster homes, supervise living arrangements, all of that that we talked about in terms of waivered services.

There's nothing magic about the state's ability to provide direct services to the disabled. The state, as an entity is not caring for the mentally retarded in the state hospitals. People are the ones who are providing care to mentally retarded. The state cannot deliver services as such. It is simply a management style that we view in this particular state.

Employees of that state's system are encompassed by the constitutional environment in which they work, and are not by themselves inherently evil.

Employees of the state are effective and knowledgeable deliverers of services. I know, I pursue them actively and especially when I have a position of responsibility available.

If they have a fault, it may be their belief in the benevolence of the state-operated hospital system. There is a place in the private sector for employees currently residing or currently employed within the state hospital system. I would suggest that the Governor and the legislature consider placing the units, the operations of the individual units in the state hospital into request for proposals. This would allow current employees, individual agencies, advocates and groups, current

employees, et cetera, to become responsible for their day-to-day management. This would also provide an opportunity for the state to move out of the business of providing direct services to residents while remaining in control of the adequacy of the alternatives which might be developed.

These requests for proposals would require continued employment by the current staff assigned to that individual unit. Assurance of wage and benefits equity within the state system for a period of at least three years, assurance of a fine illustrating of quality of life in the present location would be enriched during the next five years, by either improvement of the current physical plant or relocation of the residents into other less restrictive environments, such as foster care, instructed living arrangements or other specifically designed community-based facilities.

It would require a need and determination from the health department as long as the residents remain in the region served by the current state hospital. It would require involvement by the local county, parents, advocate, groups, Department of Human Services, licensing and program divisions, et cetera. And would importantly require a proactive stand in the Department of Human Services to the development of the appropriate rate.

It would also provide -- require proven management to financial ability to deal with an operation which provides residential program services to mentally retarded residents.

Those employees already exist within the state system. And I feel confident that those people would rise to the occasion.

Current employees and other agencies or individuals could also contract with agencies in the state, provide that management expertise to assist them during those initial development years.

The results of that effort would be as follows: First of all, we would see a clarification of the interest on the private sector to provide services to this population. It would indicate that the agency which operated the community would become individual freestanding entities, community providers, if you will, and probably corporations in their own right. It would provide an opportunity for the state employees to join together and respond to a RFP which is specific to the unit in which they are currently employed.

It will provide an opportunity for AFSCME and other communities to facilitate the response to these RFP's while still representing the employees in the state-operated systems. It would have no immediate impact on the federal government since initially the residents and facilities would probably not be moved.

It would result in a minimum of upset to the residents and guardians, such as the basic living environments we're talking about would undergo probably only a gradual change.

It would provide interesting enough a continued return on

the building that the state operates. Such a state will also be in charge of the utilization. The agency elects — that operates a program elects a state in the building. There may also be a possibility of selling that building.

It provides an opportunity for the state to facilitate private development to long guarantees, proactive rate setting, technical assistance with little or no capital outlay.

An agency can contract for state operations remaining on the campus such as day activity center services, the utilities, or other specialized treatment areas. Thank you.

MR. TAPPER: Thank you, very much. My name is Phil Harold Tapper. The role of the state program for service providers should be determined by the potential contribution of that provider to client growth and development. We now know as never before that clients can benefit most from community services outside the state hospital setting. The community provides opportunity for homelike residents, for integrated work opportunities, for normalized learning experiences, for access to generic health and support services and for maintenance or family ties.

The securing of these benefits which are inherent in and unique to the community setting is the real purpose behind the continued movement of clients from the state hospital to the community. The issues being addressed by the present studies being taken by the state financing agency are the unattended

results of this move to community services.

The intended result and the result which remains at our focus is to improve the opportunities for mentally retarded children and adults in Minnesota. We believe that it is important to maintain this client center perspective as we discussed these and other issues.

On July 16th Governor Rudy Perpich signed a proclamation which I'd like to share with you at this time.

Whereas Minnesota has citizens who are mentally retarded, and whereas an increasing number of these citizens are living in neighborhoods throughout communities in Minnesota, and whereas in the ray of support, training, and treatment service is available to enable these persons to live as independently as possible in the community, and whereas Minnesota has been a leader in developing community-based services, and whereas community-based services contribute to the quality of life for us all, and whereas each person with mental retardation has a right to live in the community, now, therefore, I, Rudy Perpich, Governor of the State of Minnesota, hereby proclaim this week of October 1st through 7th community living awareness week. The week that has just passed.

And I urge citizens to join with me in participating in activity during the special week and we join in activities during the coming weeks and the years to come. Thank you.

A VOICE FROM THE AUDIENCE: Sir, you failed to name

your provider or --

A SECOND VOICE FROM THE AUDIENCE: I'm sorry. When I was first at the mike -- I'm the Executive Director of the Association of Residents for the Retarded in Minnesota.

MR. MOORE: My name is Bud Moore, and I'm the representative of the Association for Retarded Citizens of Minnesota.

I would like to speak tonight as a representative of the Association, but I think more importantly as a parent of a retarded child. This is a philosophy statement that was adopted by our Board on April of 1980.

All people have fundamental and moral constitutional rights. These rights must not be aggregated merely because a person has a mental or physical disability. Among these fundamental rights are the right to a community living and the demeaning of education and programming and human services, all people as human beings are inherently valuable. All people can grow and develop. All people are entitled to conditions which foster their development. Such conditions are optimally provided in community settings.

Therefore, in fulfillment of fundamental human rights and in securing optimum developmental opportunities all the people regardless of the severity of their disabilities are entitled to community living. The Minnesota Association for Retarded Citizens has adopted the above statement as a basic

philosophical position in the provision of residential services.

This association believes in vigorously protecting and supporting the human rights of the mentally retarded persons to a normal living situation. This association believes that a community is the best place for people to live regardless of their disability. The community has a potential capability for serving any person who was disabled. We believe further that we have an obligation to advocate vigorously for the development of the community resources necessary to enable all persons the choice to live in the community.

we believe that any residential service, its equipment, buildings, furnishings, and pragmatic practices must be provided in accordance with the principle of normalization.

We believe that removal or segregation of anyone from society and the community on the basis of their disability is wrong. This association is a strong conservative committee to the deinstitutionalization of all mentally retarded persons, both in terms of prevention of institution of the layperson as well as a return of institutionalized persons to the community.

One method that has been used to describe the living environment is a long continuum ranging from least restrictive to most restrictive according to its proximity to the normal setting. We support the provision of services in the least restrictive alternatives possible.

The natural or adopted family is seen as the most normal,

least restrictive setting for children to live in. Support services to the natural family should be equivalent to that provided to the community-based and state-operated facility.

Likewise, the ultimate goal for residential services to adults must be to assist them to live as independently as the person as capable. Therefore, the primary goals of this organization are, one, to support those families who choose to care for their handicapped child in their home, and, two, to advocate for the resources necessary for handicapped adults to realize as independent a life as the person is capable.

We believe that the state institutions do not qualify as the least restrictive alternative for anyone. Phases such as right to treatment and least restrictive alternatives have been substituted for the normalization concept and have been used as an attempt to legitimize state institutions. However, improving institutional experience has nothing to do with more money, better physical facilities, hospital improvement plans, staff ratios and competencies. What it's really about is ending the segregation housing of large groups of people together, their removal from society, pouring more money into the constitutional setting is not going to remedy these basic flaws, the inherent unnatural setting of institution living.

we believe there is no one — there was no one who could be better served in institutional settings where the adequate community resources is available. The fact that community

resources are not adequately available is no valid argument for continuing to support institutions, In fact, this excuse has impeded the full development of community services.

When we talk about the role of state hospitals, institutions quickly digress to inaccuracies of the existing community system. We use this as an excuse to continue supporting state institutions. The consequence is maintenance of the status quo with either system arriving ultimate benefits.

Until we make a strong absolute commitment to community service there will continue to be undeveloped community support systems.

The ARC has become --

MS. KARLINGS; How much more do you have?

MR. MOORE: This is double spaced.

MS. KARLINGS: One more minute.

MR. MOORE: Okay. The ARC has become stronger in its commitment to the fundamental right to community living. We must respond to the major changes as heard in the system. Public Law 19-94142 provided for education of all handicapped children. Families are keeping children home more rather than placing them due to family support systems and different goals on the part of professional and service providers.

Expectations of families and children of mentally retarded are higher now than the children that attended public schools and grown up with friends in their community. Young parents and

their handicapped children have a resistance to a segregated setting because they consider other alternatives to be preferable I'll accept the last one given the resources, therefore, all people can live in the community.

What needs to be addressed now is how to meet the employment needs of state hospital staffing and economic needs of communities where state hospitals are located. The answer to these needs cannot be used to stop the institutionalization.

MS. KARLINGS: Thank you, very much. I really do apologize for doing this. I don't like it a single bit but it's one of the sure ways of making sure that everybody gets their chance to speak. Yes.

MS. BERGER: My name is Dorothy Berger. I'm a social worker. I've worked in Anoka for 14 and a half years and I am working in the community now for the last four years. I've been involved in the development of the community programs and have also struggled while working at the state hospital to see if programs there can be improved. I am a pragmatist. And I'm interested in the best treatment for each person in the right place at the right time.

I would like to read a statement. Unless smaller and well-staffed facilities can be developed in the community for a total of, say, 400 people at a time, it seems to me that the state hospital would continue to be needed. This is not an either/or position. Okay. It's not black and white.

I don't know whether small facilities would be an overall improvement. It might be. And the decreased size might mean increased personal care plus the advantages of living in the community.

Increased difficulties in supervising and checking standards could lead to some problems which have been encountered in nursing homes and facilities for children.

The increased information required to permit corps to commit people to these small facilities might also become a problem. There might be some advantages. People might volunteer more readily. However, facilities must be designated for particular types of problems, thus permitting better focus on the problem of the individuals. Okay. That's one point.

Another point, all clients cannot be treated in the community hospitals. I'm talking about mentally ill clients. I'm not talking about retarded. Okay. And in all 36 facilities some people need longer term care in hospitals and our present rules in hospitals do not permit this. Some people are safe with themselves, and others, some are at times just too psychotic or bizarre to be given the freedom which they have at the hospital, and which they would not have in the community placement. Many of them would be robbed and abused on the streets and some of them might be abusing other people, staff and other people at certain times. I'm not talking about their entire life span.

This is already occurring due to premature discharges from the local hospitals. The difficulties with the commitment process currently, an inappropriate placement due to the scramble to fill beds in the community.

Many really chronic patients are in need of nursing care for medical health and cleanliness standards as they have some difficulty in caring for themselves in these areas.

Both California and New York have closed the big hospitals and have abandoned their chronic patients, mentally ill I'm talking about, to the streets. Last year there were a number of 3,600 people walking the streets. Their example should be a warning to us. I don't think we need an either/or mentality when we're talking about this particular problem.

Big hospitals like Anoka are well staffed, can build up knowledge and experience in treating the major mental illnesses and could do research to improve treatment methods if given proper direction, support and funds.

They can also serve as training facilities for professionals. I believe that the state hospitals can be helped in first-rate facilities, which some of them have been struggling to do for many years, with increased staffing where needed, remodeling and replacing of buildings, designating them as centers for both out and in-patient care, and increasing their role and training and research.

The assimilation and sharing of knowledge of the various

professions found in big hospitals cannot be matched in small units scattered throughout the community. I do feel that the state hospitals have not have enough support in the past to do the job assigned to them. They care for the most difficult people in the mental health continuum and do a good job in spite of parental problems, funding, a confused sense of identity, and being ignored, and used as a scapegoat by the community.

I've been watching this dilemma for 18 years, 14 and a half spent at Anoka, and four working in community facilities.

I think that we need to think very carefully before we close the hospitals. The 30-day stay limit on stays in most community hospitals mean that we are taking people into the halfway houses, in which I work, who are not ready to be discharged. Sometimes they are having staff injured and other patients injured and it's not appropriate.

MS. KARLINGS: Thank you very much.

MR. JONES: I'm David Jones, Ogilvie, Minnesota. Quote, "Patients released from state hospitals can be found in clusters and uncared for in the poorest of neighborhoods." Jerry Joseph, Contributing Editor, unquote. Jerry Joseph, Contributing Editor, Minneapolis Star and Tribune, February 26th, 1978. That was back then.

And on the local scene here in Minneapolis, quote, "And hardly a section of the country or our urban or our rural has escaped the ubiquitous presence of ragged, ill and

hallucinating human beings wandering through our city streets, huddled in alleyways or sleeping over vents," unquote. Christopher Canal, Associate Press, Minneapolis Star and Tribune, September 13th, 1984.

That's today, and on the national scene, and includes Minneapolis/St. Paul, quote "And while the Minnesota Department of Public Welfare requires individualized treatment there is no money to make it happen. The federal government provides matching funds for residential facilities for the retarded but refuses to do the same for the mentally ill." Jerry Joseph, Minneapolis Tribune, February 26, 1978.

A 1978 report, things have gotten worse, not better. Quote, "The American Psychiatry Association saying society has turned its back on tens of thousands of homeless mentally ill urged Wednesday a nationwide system be created to provide food, shelter and treatment for these, quote, unquote, untouchables. Christopher Canal, Associates Press, Minneapolis Star and Tribune, September 13, 1984.

The American Psychiatry Association and other concerned organizations are calling for a thorough integrated system of care for mentally ill persons. They advise sickness criterium not dangerousness for hospital admittance.

As I read the Association expects the state hospitals to be the major component of an integrated system of mental illness care. Sixty and better, 90-day initial hospital stays are needed

to determine medication requirements of patients, then reentry should be easy because medication requirements change, and this is not recidivism, which is a term from criminology anyway.

The 30-day hospital stays in private hospitals at the $300 a day and more are beyond the means of all but the most affluent and are too short for diagnosis and medication needs determination.

Community mental health centers have been staffed with poorly schooled and trained personnel who do not understand chronic illness. Community mental health workers have been schooled in, quote, unquote, counsels, which is tutoring or teaching. The mentally ill require medical treatment for their chronic disease followed maybe by this tutoring or teaching.

Until the community programs are beefed up and until other changes are made such as encouraging parents and guardians to become effective members of the recovery team by reversing the, quote, unquote, family-caused illness message of the past 4 0 years, until real alternatives exist outside the hospital for the mentally ill, the state hospitals are needed and require more funding and expansion, not reduction.

(Applause.)

MR. LICHTNER (ph): I am Don Lichtner. I speak as a consumer and I also speak as a chair person for the Citizens' Advisory Committee to the Ramsey County Board for the Mentally Ill. I speak in behalf of my sister who has been mentally ill

for 35 years, and I guess at that point you would say she is chronic. We have gone through the state hospital system. We have gone through the closure of Hastings. We have gone through the community-based programs in St. Paul where my sister was shuttled from one provider of service to another because her behavior did not fit into their program.

It seems to me there are people who can live in a community, mentally ill people who can live in the community, but there are also some who cannot make it in the community and never will. Their behavior is such that they can go for a period of time, but then they become aggressive, and their behavior -- they maybe attack another person, and at that point the provider of service and community says she can no longer stay here. She has to go to another place in the community.

when you have done that, when you have gone through all the providers in the community, where do you go then? You do not pass these people around from place to place after 60 days, after 30 days, after 90 days. They need the stability to know where they're going to be, where they are going to sleep the next day, where their next meal is going to come from. So I say we will always need a place such as Anoka for the people who are chronically mentally ill. Thank you.

(Applause.)

MR. KENNEY: My name is Kevin Kenney. I'm an Associate County Administrator in charge of the Bill of Social

Services in Hennepin County, The Hennepin County Board has been on record for a number of years supporting the continued operation of Anoka State Hospital, and my remarks tonight are addressed specifically to why the county supports the continuation of Anoka State Hospital. There obviously are many other aspects in the task before you of planning the future of the state hospital system or the system and care for the mentally ill and mentally retarded and chemically dependent, but I will confine my remarks to the resolution of the County Board in relation to Anoka State Hospital.

Hennepin County has had a considerable interest in investment programs for the mentally ill and the chemically dependent. The county has developed many new local resources in recent years and has a network of services that any community would point to with pride. Upon examination this community continuum of services for the mentally ill and chemically dependent, however, does not make patient access to a state hospital unnecessary.

We support the concept of a metropolitan -- and I underline Metropolitan State Hospital — for a variety of reasons. Irrespective of the full range of community services developed, some patients will require specialized programming that cannot be readily developed on the local level.

Some of the important functions that a state hospital should meet are unique to the kind of patients that cannot be

readily handled in a community setting.

Some examples are the aggressive mentally ill person who requires a secure setting such as psychogeriatric patients who are discharged as unmanageable by nursing homes or persons who have a history of arson, sexual assaults, murder or unpredictable physical attacks where the public is at risk. These moderate to severe behavior problems generally require a hospital stay under public supervision over a three months' duration.

The many mentally ill endangered dischargee from Minnesota security hospital needs access to a less restricted hospital environment as a step to gradual integration into community living. Patients suffering from low incidence, multi-problem conditions such as hearing impaired, mentally ill, retarded mentally ill, chemically dependent mentally ill, need a specialized hospital program when all community resources for single-problem clients have been considered and exhausted.

Clients who have special problems which require ongoing medical supervision and are considered dangerous to self or others need specialized programs when their behavior problems make community placement extremely difficult.

Some chemically dependent individuals need a controlled setting when hospitalization results from a commitment process. Another reason, and this one, of course, can be addressed, is very difficult to be addressed, and does not obliterate the

other reasons that I have encountered and Hennepin County supports the continuation of a metropolitan state hospital.

Another reason is related to the financial support. Given today's funding structures there are situations in which there is no current means of securing funds for needed services to some mentally ill or chemically dependent clients in the community. The problem is heightened by the following considerations: Acute psychiatric hospitalization under medical assistance or Medicare coverage or publicly subsidized treatment becomes exhausted before the treatment program is completed. For psychiatric patients needing treatment beyond 30 days of stay in local, in-patient facilities is not financially possible and state facilities become necessary when there are no alternatives, lesser restrictive options available or appropriate,

With the constriction of private insurance coverage, with the increased limitations in Medicare, Medicaid, and general assistant medical care, we can expect a greater need for the use of state hospital facilities where the indigent, chemically dependent person, unless other means of funding acute and long-term treatment become available.

The relationship of Anoka State Hospital to Hennepin County has been one of cooperative efforts to jointly deal with each other in a coordinated delivery system for the mentally ill and chemically dependent.

We recognize the efforts of Anoka State Hospital to improve their programs and the quality of service in recent years. The addition of qualified psychiatrists, the certification by the Joint Commission for Accreditation of Hospitals attests to the significant gains made by the primary state hospital used by Hennepin County.

We hope that sufficient facts become identified to continue this needed supplement to the range of local treatment options for both the mentally ill and the chemically dependent and to support improvements in the physical planning at Anoka State Hospital.

MS. KARLINGS: Thank you.

(Applause.)

MS. HINDERSCHEIT: My name is Joan Hinderscheit, the Public Affairs Director for the Mentally Ill Advocates Coalition of Minnesota. My comments tonight will focus on the mentally ill-

MS. KARLINGS: Speak up a little louder, please.

MS. HINDERSCHEIT: Mentally ill persons and his or her needs must be the most consideration in the State Planning Agency's study. This is really what it's all about, isn't it? It is vital that the state acknowledge all components of mental health systems in relation to the most appropriate care for each mentally ill individual. Whether appropriate means a hospital, a community program, or another form of treatment, the placement

and care should be tailored to the person being treated.

Over the past decade Minnesota has developed community programs so that mentally ill persons can be treated in innovative ways, closer to home, and in a less restrictive setting.

In other words, a setting where they can reach their optimum self-sufficiency. The needs for more of these options is great. This need cannot be met until all parts of the system work together to create a cohesive system, a system where the hospital is an important part of the continuum, a system where community programs are equally important, a system where care givers are knowledgeable about each other and cooperative, a system where government officials are aware of and willing to fund quality programs, evaluate them and approve them, a system with financial incentives where the dollar follows the community, a system which is innovative, creative, sensitive and cost effective at the same time.

The Mentally Ill Advocates Coalition urges the State Planning Agency to develop highlight projects, projects which take all of these points into consideration. We urge the State of Minnesota to take a strong leadership role in meeting the challenge of the cohesive mental health system which puts the life of mentally ill persons as the number one priority. Thank you.

(Applause.)

MS. ZIMMER: My name is Norma Zimmer. I'm the mother of a son who has a dual disability. He's mentally ill and mentally retarded, and I'm also a Board member of the Mental Health Advocates Coalition.

Our son Michael was in Cambridge State Hospital from February 1979 to October 1983. He was in Anoka State Hospital from October 1983 to April 1984. State hospitals need to be upgraded if they are to remain open. Employees, including the professionals, should be carefully screened, not only as to their training but monitored in the way they treat the patients. No matter how the severe the problems presented by some patients they are human beings entitled to be treated with respect. Family members also need to be treated with respect, not as interfering amateurs. Abuse would be less prevalent with better employee monitoring and screening.

Michael was put in restraints at Anoka for aggressive behavior. Seclusion would have been adequate under the circumstances. I read some of the notes about his care when he was restrained. We couldn't understand why this inhumane treatment continues to be used. I think the idea of self-abuse if not restrained is a cop-out.

After an aggressive incident at Cambridge the Cottage 14 staff insisted that Michael be sent to St. Peter's Hospital, which would have been very inappropriate. No mention was made of Michael's welfare. It was only through the intervention of

a hospital advocate, legal aide, and Jonathan Ball, this did not happen. Medical mismanagement was involved but this was denied.

The advocacy system in the hospitals is very weak. Advocates in my experience want to stay in good graces of the staff and the executive officers, so overlook issues that need attention. For example, the behavior modification program at Anoka in Cottage 9 is rigid and applies the same curve to each patient regardless of individual levels of function.

Michael could not handle the rigidity, but no options were offered in spite of my knowledge of his functioning level in trying to work with the staff. The program director was very dogmatic and the advocate was not helpful when I solicited his aid.

Program at Cambridge was also inadequate when Michael was there. The public school gathering program was effected and geared to individual needs and contrast to the hospital program.

The level of cleanliness at Anoka at Cambridge of the hospital and the patients is very mediocre. The bathrooms are abominable most of the time and visiting rooms at Anoka are very depressing, not clean and very dismal. Patients either because of medication levels or generally low functioning walk around stoned and dirty. I can't find any excuse for this condition.

The state hospitals are generally better than in the past decade, but the need remains for a more humane treatment of the residents, better programming, medication control, upgraded

health standards for the hospital and patients and a more effective advocacy system. The ideal situation is placement in a community.

Institutionalization does not promote independent living skills nor does it allow anyone to develop to their optimum level of functioning. The patient and his needs must be of the most consideration in the state hospital.

(Applause.)

MS. VOLLER: I'm Joan Voller. I'm a Board member of the Medical Health Advocates Coalition. I'm a parent of a daughter at the Anoka State Hospital at present. My daughter lived at a residence in St. Paul for seven years.

The staff is very helpful. She was hospitalized, however, once or twice a year during the seven years because she would — my daughter would, could reduce or eliminate the prescribed medication. And before the last hospitalization she went out during the day and drank beer, smoked pot, was at a bar on University.

She attended a drug and alcohol abuse program at Ramsey Hospital for two weeks. And then she stopped going, even though she was supposed to continue for another two weeks. She returned to the residence. She struck a staff member and was rehospitalized for another two weeks at Ramsey. I then had to sign papers for Anoka.

And I thought she'd at least be safe there. I just

returned when I walked in this room from seeing her for the first time after she had been at Anoka for a month. And she is not able to get away. She looks infinitely better. Everything Norma Zimmer said about the appearance of the Call 9 — but for some people, for instance, my daughter, for her to be able to get out during the day, living in a center doesn't work.

MS. KARLINGS: Thank you.

(Applause.)

MR. VEDDER: My name is Peter Vedder. I'm Executive Director of the Minnesota State Employees' Union. We represent approximately 4,000 of the workers in the state hospitals.

I personally have been involved in the issue of the future of the hospitals since I first came to Minnesota in 1974 with our Union legislature. It's our belief that these next couple years can be as significant in terms of the future of the hospitals, and in particular for where we're going to go with the care of the retarded, as anything we've seen since the early 70's and the filing of the Welsh suit.

One of the real problems in terms of where we go next — I don't think it's a secret to anyone in the room — is we're at the point where the conflicting needs and rights of residents, parents, the communities of workers, is coming down to the line. Up to now Welsh could be met, the institutionalization could take place, the employees had their jobs, the communities had their income. Hastings closed, Rochester closed, now to

We think it's time that we stop fighting each other in trying to see who's right and who's wrong and beating ourselves up -- and that's what we've done for ten years — and start to move working together with everyone else willing to do so, to take the next significant step in approving the care of the retarded in this state. And to us, to keep part of that is getting the state into the business of providing community care.

We're looking at the current situation, and lack of funding, the waivers coining in, too many beds, the highly fragmented county/state/private system, and we think that to meet Welsh numbers now and meet waivers' numbers now, one of the best way to do that is to get the state in the business, SILLS, in terms of day programs. We think our people can do that well.

I'm glad to hear Mr. Baldus thinks not all public employees are inherently evil. We acknowledge we too are born with original sin. We don't think all private people are inherently evil, just most of them.

We think that the time to start is now. I never thought our members would come to this point. The folks want to do it. They really want to do it. Does that mean that Cambridge closes? I don't know. We'll deal with that when we get there. That's a number of years down the road. Should we be closing out MI? I would agree with everything that's been said about Anoka, the placing of MI hospitals in the system, same on chemical dependency.

deinstitutionalize somebody just decided to close them to save. money.

if the system's left to go as it is now going there is full assurance that sometime by the '89, '90, something will close whether it's Rochester or whether it's Fergus Falls, Willmar, something is going to close.

There really has not been a sufficient consensus, political consensus or political will to try — in our opinion, to try to address this and make what happens next move in a constructive anner that meets legitimate needs and rights of everybody to the extent that's possible. It's been going on the assumption that the needs of the community, of the employees, of the residents and relatives, all of those by definition conflicted with each other, and which collectively have not been doing a good job really in meeting any one of these needs and rights.

Ten years ago if you asked our members, our hospitals or community facilities, better members would have said hospitals are better. They would have given you 4,000 different reasons and be absolutely convinced in their mind that there was no way the community would be better.

If you ask our members that today, that's not the case. And that's a big change in ten years. There's a major belief by our members that the community is good, that significant numbers of the people now in the hospitals, in MR can and should be there. Yes, these folks are also concerned about their jobs.

But we've got to start and this is the biennium to start with and we hope that this report and study can get this ball rolling. Thank you.

MR. LIVON (ph): Toby Livon. I'm the parent of a 33 year old daughter who is severely mentally retarded and has severe behavioral problems. She has lived in two state institutions and in two community homes for the past 23 years. For the past 13 years I worked in the MR field as a professional planner, and I worked as an associate with staffing and serving of needs of the metro area, intermediate care facilities for the mentally retarded.

That work has given me an insight into the organizational, operational and financial basis of over 70 group homes. It is from this dual perspective that I present my remarks in support of ending the use of state institutions for persons who are mentally retarded.

Most individual placement in the community may not be ideal. In the last decade the grade of the deinstitutionalization in Minnesota has not resulted in wholesale substandard community placing of the mentally retarded people. There is a growing body of documented evidence that supports the contention that moving to the community from large institutions and improving the rehabilitation of persons who are mentally retarded.

Deinstitutionalization is a practice that is accepted and promoted by the leading professionals worldwide. To continue to

debate, if we should proceed, is not in the best interests of mentally retarded persons. And it is in their interest that I propose the following issues be addressed.

Parent concerns. These concerns include worry about parent rights relating to residential placement of their sons and daughters, continuity and stability of care during their lifetime and after they die. The legislature and Department of Human Services through the county social workers should actively advise parents that their input is part of this, and that there are mechanisms such as case management, guardianship, and conservator ship in insuring monitoring of continuity and stability of placements during the lifetime and after the death of parents.

All parents should join together in helping to establish the best possible community-based service system rather than fighting it.

Community impact. While communities are concerned about economic distress that may result from the closings, no town or city in Minnesota or elsewhere to my knowledge has suffered severe economic depression as a result of state hospital closures. Nevertheless, these economic fears must be prelated by well planned activities to find alternative use of buildings, such as establishment of regional correctional facilities, and the fate for overcrowded prisons is the most notorious problem in the corrections system.

Employee concerns. I believe providing job assurance that include portable benefits, retraining and transfers could do much to mitigate the opposition of state hospital staffs and their union to deinstitutionalization.

State operated facilities. The state would put itself in the position of conflict of interest if it were to operate the community facilities.

The role of the government is to plan, regulate and find, fund human services. The state could, should continue to use private operations, but establish the zero restraint of admission policies that providers may not avoid hard to care for people.

I just have a few more. Quality assurance. One factor that would diminish most of the concerns I've mentioned is the system of good quality controls. It requires that internal that is, governmental mechanisms be in place, such as competent and responsible case management and regulations with expansions that are effective deterrents to substandard services.

It also requires external monitoring such as citizen and patient monitoring teams for which there are several effective models.

I suggest that the mentally retarded persons must be our primary concern. We owe this much to those who have lived so long this decision that they begin to live in the most culturally normal setting in which their health and

rehabilitative needs can be met. It keeps 2,000 Minnesota citizens in more restrictive settings than they need to, and puts their needs to a lower priority than people living in the state hospital communities or the state employees or well meaning but fearful parents.

Persons who are mentally retarded have been held in lower priority for all of history. To continue to hold them hostage, to out mode aggressive attitude and expectations is unconscionable and unethical. We have a moral imperative to work, and that all mentally retarded persons will be housed in dignity.

(Applause.)

MR. HAGGERTY: Mel Haggerty. I'm a parent of Janice, age 32, residing in Faribault State Hospital. I'm active in ARC, and past member of Minneapolis, Minnesota, Housing Regional Vice President of the National Association, Secretary of that Association.

I'd like to speak in opposition to my good friend Toby Levon, who just spoke, and Bud Moore, who also just spoke, who have been active in the ARC movement.

I totally disagree with their position that all state institutions should be closed and all people who reside in state institutions are being deprived, they are being denied the right to be integrated in the community, their rights are being deprived and everything else.

I think in the old days -- and I'm sorry to see this have to develop -- but in the old days, I, for example, even today respect Bud Moore's selection for his son, because I know he would make the right decision. I also would respect Toby Livon's decision, but I frankly do resent some of these so-called experts, and I found experts always to be wrong. It's just a matter of time.

But I resent them telling the 90 percent of parents and guardians who have sons and daughters who are adults living in the Faribault State Hospital and who want to have their sons and daughters remain there because they believe their sons and daughters are receiving the least restrictive treatment. They are the least restrictive place. There is more stability. The staff are higher paid. There is less turnover. There is more experience. There is more diversification. They do have a doctor who's right there. They don't have to go downtown Minneapolis and wait two weeks to get an appointment or to wait two hours in the doctor's office to be seen. The doctor is there. The nurses are there. The physical therapists are there. The OT people are there. The psychologists are there. The behavior management people are there.

These people are there and they are on the spot, and, frankly, the last five and ten years I've seen dramatic improvements in the Faribault State Hospital where my daughter resides.

Talk about conflict of interest, some people say, oh, the state shouldn't be in the business. I've got clients, my friends, who have kids in little group homes for six and eight. Let me tell you some of the conflict interests there.

The doctor who treats all the patients is on the Board. The grocer who provides all the groceries is on the Board. The furniture man who sells all the furniture is on the Board. And I can tell you if you think there isn't conflict of interest in some of these places, you're wrong.

And as far as monitoring and quality assurance, we have a long way to go in every place. But my good friend Luther Grantwood and Lou Ray told me that quality assurance and monitoring of services in the community is much less pronounced in quality than what you find in the state institutions. The state institutions are monitored by everybody. It doesn't mean we can't improve them. We must improve them. But they get more monitoring by more people and sometimes by the so-called outside experts who we import from other states who have much less quality programming than we have in Minnesota to all of a sudden come up with little reports that tell you certain things that you've got to do this.

I had a client who just called me this week. She has a daughter in a group home in Lakeville, Minnesota, eight people in the home, five retarded men and three retarded women.

Her daughter was sick this weekend. She was in bed. She

was badly beaten by the other residents. Why? One of the staff people was sick, didn't show up. The other staff person was out supervising the young men mowing the lawn. The Board isn't even notified by the administrator. It isn't notified. Finally the Board finds out about it. They have another Board meeting and then the administrator tells the parents and the Board members you can't ask any specific questions about anything.

Now let's face it folks, you can have a business in the community. I've heard all kinds of parents who have their sons and daughters leave Faribault, come to the community, be shifted around in seven or eight different places, be over drugged by local physicians who don't have anywhere near the degree of knowledge and expertise in treating certain disorders that you will find in the Faribault State Hospital. I know a number of them have gone back to Faribault and are doing damn fine now whereas they were over drugged in the community, not the institution.

And I believe we need all of these options. I know that some people can do better in the community. There's no question in my mind. And almost all of the high-function people are now in the community and out of the institutions. And I don't want to see us — and some people say, pooh, pooh, we don't have the national disgrace we've had with mentally ill in their deinstitutionalization program well, I've seen it in other states

My daughter Mary who's in Chicago and she saw the big

institutions for the retarded closed, and she saw them placed in downtown motels, and hotels rather, rat infested where the operators of those places even took the $35, SSI money and if they walked out in the street their money was robbed, they were raped, robbed or what have you. Now, damnit, it's happened in Illinois. It's happened in Indiana. It's happened in Missouri. it can happen here if we adopt and promote the present plan of Title 19 waiver and combine that with 2053.

Title 19 waiver according to the rough draft report I saw from Hennepin County wants 31 people out of Faribault this year, 40 the next, 40 the next, 40 the next, and 40 the next for a total of 191 of about 400 people from this county who are in the Faribault State Hospital who are retarded.

Now I can tell you if you're going to force all those 200 people out of Faribault in that period of time, where could they possibly go? Then you've got to force 400 — rather 200 people out of 1CF homes. Then you're going to have the parents whose sons and daughters are now in group homes mad as hell because they're being tossed out, and saying you could live independently or live in a foster home or you can live somewhere else, where those parents may say and the social workers may say and the providers of those group homes may say, hey, this person isn't ready for this kind of living.

This is the best place, this group home. The community for our person. They'll say that, but what does the county have to

do? If we're going to have – if we can't spend any more money, we can't have any more ICFMR facilities in the community, the beds are frozen, the money is frozen. What will happen is what happened in Illinois. When you freeze the group home dollars that are in existence then you're not going to be able to give raises to your staff, you're going to have more staff turnover, you're going to have less quality. In fact, I think you will have dumping in the community contrary to what many people think, if this plan is allowed to go and if 2053 is adopted.

I think we need all options. It doesn't mean that in a period of time sortie institution may not have to be closed. But what it does mean is that we ought to respect the rights of parents who nowadays, frankly, are being told that they have to go to court and some attorney has to be appointed for their son or daughter who has a biased against all institutions, and that attorney then is supposed to fight all the way through to the Supreme Court, who gets paid every time he goes, and he is supposed to fight it all the way, even though that retarded person is so profoundly retarded she can't talk or he can't talk and they, of course, never talk to the parents. This is an adversary's system. You can't possibly find out anything from the parents.

Well, I can tell you, some of these guardianship laws and some of these commitment laws as they pertain to mentally retarded people have got to be changed by the next session of

the legislature. There's more money going down rat holes unnecessarily paying for a lot of expense. And I just had a client today called me up and they found out that is what was going to happen to her. I had to go down and attend to that little matter.

I'm telling you, folks, this is a serious problem that we have to respect each other's judgments as to what is best. And I respect anybody who says my child should be in the community. I respect the right to that. I've fought for community services all my life. But I also know there are certain people who can do much better in a state institution than they can in the community service. And frankly, they aren't to be kicked out every five minutes and then to go from group home to another to another, if you have a state institution.

(Applause.)

MS. KARLINGS: Thank you. Any others?

MR. TERBUS: My name is Sylvester Terbus and I appreciate several remarks here. I don't know if they meant that all people can live in the community. Most maybe can live in the community. That all institutions are evil, I don't think all state institutions are evil. So I am here in kind of a defense of the state institution.

My daughters, three of them, Regina, Kathy and Theresa went to Cambridge in '58, '59 and '60. We've been active in retardation and the problem of retardation for over 33 years.

We've fought these battles, many times gone to the State Legislature and fought in the county level and all that, and it seems like it's just another return to the same situation.

At that time when we took them there, there were 2,000 residents at Cambridge. At the present time there are about 345.

I wish that everyone *on* the State Commission who had mandated the closing of the state hospitals would visit Cambridge — and we assume it's the same in the other state hospitals -- and you see the type of resident who is still at the hospital. They are profoundly retarded, the most physically handicapped, the recidivists, and some of the most basically weak children you can imagine. Most of these residents receive physical therapy, occupational therapy and special treatments at least several times a week. Most of them cannot dress themselves feed themselves nor are they trained. And they desperately need one-on-one care.

In a recent article in the St. Paul Dispatch, October 3, 1984, Shaun T. Kelley wrote that it costs about $135 per day per patient at the state institution, and he offered the sum of $30 a day that it would cost to house a patient in the community. When you add to that of the community placement the medical costs, the transportation, the therapy costs, the sometimes one-to-one care, and most of the residents, most of these residents, it would well come over $135 a day for community care.

A suggestion from those of us who have had much to do with the state hospital care for over 25 years would be to close four of the state hospitals and upgrade the care of the other four, and do it in kind of a regional basis, one in the North, one in the Central, one in the South, and perhaps St. Peter's and Anoka.

The suggestion that has already been made that one option could be made to keep all of the hospitals open and downgrade care. And that, I believe, would be unconscionable. That would be unconscionable. With the freeway system in Minnesota the problem of housing residents close to Faribault residents is not the problem that it used to be. Realism has get to be one of the main reasons for decisions made concerning these hospitals.

There will be an end to the money available for community placements before the Welsh concept degree can be fulfilled as written. And while they're supposedly meeting on the Minnesota Law Chapter 645, Title 19, which I know very little about, but I believe it does set up the waivered services. Am I correct in assuming that the Medicare funds are used to finance this particular operation? How long will it be before how much is put into this Medicare?

What if the budget balancing effort of the Reagan administration, Mr. Stockton, for instance, would consider that that's one of the things that they can cut back on? Is it back to the nonexistent state institutions then?

(Applause.)

MS. KARLINGS: Thank you, very much.

MR. GRANTWOOD: My name is Luther Grantwood. For the last 12 years I have been one of the attorneys for the class plaintiffs in the case now known as Welsh versus Levene. We've outlasted four commissioners. I suspect we'll outlast Mr. Levene That's nothing against him. It's just the way things go in the world.

We have had a situation in this lawsuit because on one hand we have fought vigorously for increased staff and better conditions in the institutions and on the other hand oppressed vigorously for depopulation of the institutions.

I said before and I will say now, although the consent decree in Welsh will not require on its face the closing of any institution, if the net effect of the years of work that we have put in on that lawsuit is the closing of the institutions for the mentally retarded in Minnesota, I will think we have done a good thing, if there are appropriate and adequate community placements available. And I recognize, I think, more than some might realize how serious and big that is.

It was good to hear Keith Bender indicate that the time has come up to plan for the future. And I think that is an approach that we ought to take and the focus of it ought to be for the state hospitals as well as the community facilities that the quality concerns program really works.

If there is any conclusion I have come to in the years that

I have spent walking through every room of the retarded persons in the state hospitals and throughout a lot of group homes around the state, it is that we have a serious crisis with regard to quality assurance in both areas.

Licensing is one mechanism. It's supplied both to the state hospitals and to the community residential facilities. There are state hospital buildings or units with both ICFMR certification and with a Rule 34 license in which the type of program required is simply not being provided.

And likewise, there are community facilities that have ICFMR certification and Rule 34 licensing in which the kind of program that is necessary is simply not being provided. And I assure you folks I can't in three minutes, but I could document both of those.

There is accreditation. Faribault State Hospital received its ACMR teaching accreditation within the past year. The type of program provided children who we are intimately familiar with. And the cedar and maple buildings that are at Faribault State is indicative of the rest of the places. It is inconceivable in my judgment that that facility could have been corrected.

We have another mechanism for quality control. It's called case management. It's the county social worker. And it has not been a system that has worked effectively. The county social worker has responsibilities both at the state hospital and at the community residential facilities. They are overworked

generally and under trained in some instances.

Now why does this situation exist that I say exists? Again, I can't in three minutes document it, but I've spent some time in a large pile of paper which you folks, I think, have access to it in the Department of Human Services. Now if you want to look at it, they complain about the paper, but they ought to be able to find it.

We're here talking about a depopulation policy because that's what the statute that you folks are operating under refers to. It refers to steadying the effect of depopulation of policies of the state.

Now I limit my comments with respect to the persons that I've worked with for the last decade, persons who are mentally retarded. What is that depopulation policy? I know one of them, and it's in the Welsh consent decree. It says by July 1, 1987 there must be 1,850 residents in the state hospitals that are persons who are mentally retarded. I know there's a depopulization policy in the Welsh consent decree that says placement must be appropriate both with respect to residential and day programs. I know that the Commissioner and the Commissioner's staff have been unwilling in any official pronouncement, and largely unwilling in private to articulate what they consider to be appropriate community placements.

So we end up with the interesting situation where eight residents from Hennepin County leave the state hospital and go

to a 165 bed institution in Ramsey County. We have the situation where community residential facility demits a resident, the resident goes to Faribault, and the next day somebody comes in the back door from Cambridge. If there was a problem at the community facility it was not considered so far as I know in the placement made from Cambridge.

The fundamental problem that I see is there is little direction to what is going on. It is difficult to look at the question of depopulation or deinstitutionalization or closing an institution. This group needs a jolt. Okay. For 30 seconds.

MS. KARLINGS: I'll turn it off for 30 second.

MR. GRANTWOOD: This is just a couple weeks before the election and Rudy was running, and I said, come on folks, we know what's going to happen. Rudy is going to get elected next week, and two years from now the IR is going to turn all the DFLers out- What are we going to do? Close Moose Lake. The same way we closed Rochester. In my judgment, irrational judgment. It was not based on any fact. And I frankly don't hold out any hopes for a rational judgment as to which institutions should be closed. It's just not in the cards. I don't respond to that. I'll get back to — it wasn't that good of a joke.

We've got the Moose Lake run, the folks are sitting in the car that day looking blanched. They charged me .45 a page for copying, so I suggested that they become a copy of the North and

that didn't get very many laughs either.

The study that you folks are doing defines terras, but it's very limited. It looks at buildings, it looks at the effect on the community, it looks at the effect on the labor force within the institution, and those are very serious and very important issues. But if you look at the state in terms of what it has to say, it doesn't say very much about the residents in the state hospital, the mentally retarded or mentally ill or chemically dependent.

Now I think in the way you have conducted this study you have kind of filled in a blank, but that is an interesting blank in the legislation because it gives you precious little guidance from the legislative branch as to where this whole system ought to be going and how you ought to weigh and balance these things. Precious little direction from the executive branch and it wasn't until Harold Tapper talked a few minutes ago I realized we had Community Living Awareness Week last week. That's kind of a major executive pronouncement that doesn't get a lot of play.

Early in your hearings Robert Karl came from Rhode Island and said, "If you don't know where you're going, any road will do." I leave you folks in putting together your study, anything that I would like to say to the legislature and the executive branch is make up your mind, folks, about where you're going, because otherwise any road will do. And I will be up here ten

years from now talking about the lack of quality assurance in state hospitals and community facilities.

(Applause.)

MS. CAINEN (ph): I'm Clara Cainen, Ramsey County Citizen Advisory Committee and the parent of a mentally ill son. We know something about the system. I'm here saying something because my friends may not give me a ride home unless I make some contribution. And so seriously, I'm trying to think what can I add to the many things which have been said this evening.

Primarily what seems important to me is that we are grouping the target groups that are serviced by our state hospitals more as if they are similar, rather than different. Therefore, I would urge us in pursuing these issues that we look very carefully at the decisions we are making about the differences among the groups.

Secondly, in our experiences – and now I'm talking both as a family and as observers of the community scene -- there isn't any way that we can assess with support and with comfort the community resources, and perhaps Dorothy Berger said this with a much more thorough basis as a working professional, but certainly I can support what she said in terms of my experiences.

There isn't any way that the society can responsibly wipe out those facilities, the state hospitals, which are an established resource with all their deficiencies until it has

done a more adequate job in filling the so-called fantasy of community resources, particularly for the chronically mentally ill.

in my judgment, and I can even say this as a recently retarded professional, it is a scandal that the professionals working in the field have not assumed more responsibility for evaluating the inadequacies of what goes by the way of community resources. I do not know the retarded problems. I cannot imagine, however, that whatever has been said here by the consumer, and I respect your judgment, that the problem for the retarded is not going to rise up and kick us in the face again as we have placed all these problems in separate community resources. For the chronically mentally ill it has not yet worked.

(Applause.)

MS. KARLINGS: I think there were some other people that started to get up. Yes.

A VOICE FROM THE AUDIENCE: My wife and I have been parents ---

MS. KARLINGS: Speak a little louder here.

A VOICE FROM THE AUDIENCE: Yes. My wife and I have been the parents of a retarded child for the last 35 plus years, in which time we have seen all progress from Cambridge down to Hastings and up to Faribault. It's been so orderly moved along and he got used to things, but here about two or three years

ago we saw a marked improvement in the type of care which he received and the efforts targeted to find out every way they could help him. This same thing in Faribault occurred with all the other children that we saw down there. And believe me, we've been there many times. Our heart goes out to those who don't have visitors. I wish there was some way we could get the message out that they should get down and visit their retarded. And if they don't have one, pick one. But I am one who's definitely sold on the campus type of institutional or facility treatment.

Now there may be some who are qualified to live out in the neighborhood with a fence and a 40-foot lot or an 80-foot lot on busy street, but there are others who never will be. They are safer, they can wander at their hearts content on the bounteous campus of Faribault and of the other places.

Let's hope we can keep as many as possible even though we may want to get efficient and use certain pilot installations, North, Middle, South with satellites. And possibly use group homes in the neighborhoods. But I want to applaud and back up everything that Mr. Al Hecht has told you because I know how long he has worked, much harder than myself in the field of the mental retardation. Thank you,

(Applause.)

MR. CASTRO: My name is Dan Castro. I'm Director of Cheynew (ph). We have a six-bed home and we're located in

St. Anthony Park neighborhood of St. Paul. There are six people who live in our home and we opened in March of '83. The six people we have are the same six people that we started with. We have three men and three women. All of them are from Cambridge State Hospital. All of then have labels of being severely or profoundly mentally retarded.

I'd like to tell you first a little bit of our people. Debbie is someone whose forehead is all scar tissue from years of having banged her head while in a state institution. I'll give people at one of the state hospitals credit for having done some work to get her placed in the community. She has still had some self-abuse of behavior when she came to us. Now if she wants attention she says, "Attention please." She gets it.

Judy, when she first came to us, you couldn't touch her. She had been so physically abused in the past she would shy away. Now she will go out, initiate hugs with other staff.

peter, who is or had been nonverbal for the first 20 years in his life is now starting to talk.

Franklin in 1977 was one of the first people in the state hospital who was part of their drug experiments. At that time when he was on 400 milligrams of Melaril(ph). They abruptly withdrew his medication. He had seven grand mal seizures in two days and they finally realized that, whoops, they might want to change something. Currently with a very gradual reduction, and *I* will add the people at the state hospital, when

we admitted him, warned us that it's best to go slowly. He's doing really well. He's at 225 milligrams of Melaril. He is now off of his Clogentim (ph) and will be beginning to work with gradually reducing his Chlrohydrate, which is at 500 milligrams.

Marilyn, very much of a loner when she moved in and very timid is now more verbal, says more words, her vocabulary has more than tripled, and she's a lot more assertive than when she moved in.

Steven, after he moved into our home, the state hospital warned us, they figured about two weeks he'd demolish the entire house. Well, he's become kind of our model person there. And I would say one of the most gentle people who lives in our home. Even after 30 days of living there, people from the state hospital said they had never seen him looking so good or acting so calmly. He's also doing quite well on his psychotrobis (ph) reduction.

Yesterday afternoon I spent time with people from Cambridge State Hospital all afternoon. Three people from there visited me at my home and then we went to the group home and they are interested in starting a community facility.

One of the things they are most struck by was the fact that we have at least two people on duty, two staff, for our six residents when residents are away. Often we will have three.

Ratios for similar people are one staff per person for eight, sometimes one staff person for 16. They were very good

people that visited us. I am pleased that they are starting a facility. I wish them luck. I will be of whatever help I can to them. I think that when Peter Brenner said that the time has come for people in the community and people in the state hospital to work together, I think he's right. I think there is outstanding people in both systems. I hope that all can work together as old and new members of the private sector in meeting service needs of people considered mentally retarded. Thank you.

(Applause.)

MR. QUARTER: My name is Ralph Quarter. I'm here to represent the Minnesota Association for Persons with Severe Handicaps.

MS. KARLINGS: A little louder.

MR. QUARTER: It's real interesting because this format sets up a stage where we have several, maybe at least 100 people talking about several really complicated issues, and people have done it very eloquently.

I'm going to speak about one issue that I think is a personal issue and it's an issue for the organization I'm representing tonight, and that is the issue of the clients themselves. Each person really has mentioned them as an issue, but that is my focus, and that's where I'm going to put my emphasis.

When we talk about institutions I think we need to look at what is the purpose, why were they created, what are they for,

who are they for, what is supposed to happen with them. And I want us to look at that contention.

As we talk, as we look at the issues, are we trying to protect the people that are in those institutions? Are we trying to protect ourselves from facing the problems that a community has to face about different kinds of people, people who do different things at different times. In our community we handle people who speed, who drink, who have fights, who do other kinds of things. We deal with this in our community and other societies might say, they would not tolerate that and they would lock up those kinds of people.

Maybe like society may not tolerate alcohol abuse or spouse abuse. Those people, they could lock up. Well, I think we're doing the same kinds of things with people who have different kinds of behaviors than we do.

Now again I'm addressing people who are severely mentally handicapped, that's my experience, as a teacher, as a person working in the educational field. I think we need to consider these criteria though for other people also. Are we just here to protect those people or just to protect ourselves or do we want to help them develop skills that will make them function better in the community that we all live in? We all have relatives who have disabilities of one sort or another. Do we want to just protect them or do we want to help them and give them some skills?

I worked with some model programs in the Metropolitan area. I know of model programs around the country, and I do believe that there are things that we can do to help people with disabilities. And I think we can help them, but there's another process here. Again, it kind of involves protecting ourselves, and that is that we learn skills to interact with people with disabilities. We can't just focus on interventions that help people with disabilities. We need to know as someone in the community when someone comes to the counter, if I'm working at McDonald's, and someone doesn't talk, I need to learn how, maybe, there's something I can help with in ordering, in getting something.

Severely physically handicapped people, severely mentally retarded people can do those kinds of things. They actually can go up and tell someone what they want. They may not use the same language. They may not speak, but they may give a picture, and all they might be able to do is spell it out and show someone. The issue there is that they have expressed an intention. And as a result they can get something. They're receptive in that manner.

so basically what I'd like to address tonight is what are the issues. My issue is providing the best possible placement in the community for people with severe handicaps and a hope that we're not just trying to protect them from ourselves. I hope we're trying to develop skills in all of us. Thank you.

(Applause.)

MS. KARLINGS: Are there any other speakers? Anybody else have anything that they would like to say?

MS. GAY: Well, I'm Mrs. Emma Gay. I've been associated with Faribault for a long time, and from what I'm hearing here tonight I'm just a little concerned about the fact that we're going to start taking vulnerable individuals and start shuttling them, saying, you belong here. Then they get there, and they don't act like they should, somebody says, nope, you belong there. Where are they getting their love, their care, their security? And that is one of the things that the MR really need, is just plain good old fashioned love and security. They're like the man hugger says, six hugs a day. If they're going to be shuttled from this one, they don't develop friends. They don't stay long enough at this place. They go someplace else. Where are you going to get that love? Where your state gives it, they have got the campus. They know the place. They know how to get from building to building. They don't worry about cars. They don't have to because everybody in the state institution is aware that they are not capable, and yet you want to put them out in this busy community where even some of us have got two legs have to run awfully fast to get across the street.

And I think it's really unfair that we think we can just pick them up, shuttle them here, and brush it off, say, nope,

he's going to go there. That to me is just plain abuse. Because a person can't cope with his mental retardation, and you're abusing more by placing him into more and more situations where he's going to have to go.

(Applause.)

MS. KARLINGS: Thank you very much.

A VOICE FROM THE AUDIENCE: I work for the Association for Retarded Citizens, and I hadn't planned on really saying anything, but I just decided at the end of it I would.

Over the last few weeks I've been traveling around the state and meeting with parents and elected officials and candidates and that type of thing. I just wanted to bring forth a view that I've gained in these past several months. It's from parents who have young children who are profoundly mentally retarded, perhaps multi-handicapped, and talking to those parents

I can assure you that in looking into the future, they do not want their children to be in the state hospital. They want their children. Not only do they not want them in the state hospital, they don't want them in a community group home that is 70 or 80 miles away. The purpose for that is they are the ones that want to give their children their love. You asked about where do they get their love. They come and give it. They don't want someone who's paid to give them their love. They themselves want to give it. They want the grandparents to be able to visit them. They want their brothers and sisters to

be able to interact with them, and they want their children to also interact with the people, the friends that they have made in their integrated schools.

And I think as we look towards the future we have to look at what the young parents wants, what they're saying, and what their new needs are. And they are different than parents whose sons and daughters are perhaps in their 30s and 40s. I just wanted to bring up their viewpoint. They are more likely not to attend an event like this.

MS. KARLINGS: Thank you very much. Any other comments?

A VOICE FROM THE AUDIENCE: I would like to respond to what Sue said because I think again this goes back to my concept that I think some of the younger parents now in this day and age with better education systems and with better community services that didn't exist years ago do have an opportunity, more than at least, to keep their children at home with them while they are children. This is an applaudable idea if you can make it work, but there are still going to be some families where keeping that child at home would cause a divorce, cause a split, as much as all of our good intentions are. We'd like to believe that won't happen, but there will still be those cases where that child must have a place to go. And I think for that other child, foster parent or small group homes frequently make sense.

On the other hand there are some children who need such

intensive nursing and medical care, who are so medically fragile, who are retarded that they need something a little bit different than that. I have some fears that I have expressed before.

My friend Bob Johnson, former County Attorney of Anoka, who belonged to the National Attorneys' Association, County Attorneys' Association, has spoken with a number of county attorneys across the nation. They have not found, especially in the East, but they have not found anyplace in the country where you've had good monitoring or even had the capability of good monitoring of foster homes where you had one child or two children in the home. Now it's nice to say that we can have all these people trained and experienced and what have you. But from my experience I've seen some wonderful county social workers. Frequently when they get good and experienced and they got the heart in the right place, they're knowledgeable, they're smart, and they get that experience, however, then in order to get an advancement they get out of the system. And so you're bound to have a lot of new untrained people coming in to do a lot of these things. Where did all the so-called experts come from that are going to do all of this quality assurance work and monitoring with all these places? I don't see it in the cards, and I do see a lot of experts coming out with very decided biases against the programs. I think that's unfortunate because I do think we have to work together to have more options, not fewer options. I think the state

institutions do provide that.

One last point is the Faribault Hospital, I think there's somewhere between 30 and 60 people there who at the present time are parents, and the institution and the county social workers have agreed that it would be nice to find a given type of community placement for these people. There aren't any available right today, but there are only 30 to 60 at Faribault right now today where that kind of a plan has been developed and there aren't the placements in the community for them.

Now what I'm concerned about in the application of Title 19 waiver mechanism is that we are going to be forcing out 30, 40 a year, out of Faribault State Hospital due to ICF. We're going to be forcing 40 people a year from the ICFMR group homes into a different place.

I think that the maze of this kind of bureaucracy of shifting our people against their will, against the will of their parents, is going to cause a chaotic type of program. I think we're going to deny people in the community who have sons and daughters who want them to be in the similar homes or in a foster home or in a small group home or in a semi-independent living unit. We're going to be denying them places because we're going to be forcing other people out of placing where they feel they're getting good treatment, and we're going to deny the people in the community who want: their sons and daughters in community facilities. We're going to be denying them places.

I think we are going to have utter chaos in this entire thing if we're going to force large numbers of people out of state institutions irrespective of the wills and desires of the parents and the staff and the institution and the county social worker and just because somebody has an idea that you can live better somewhere else. Thank you.

MS. KARLINGS: Thank you. Are there any other comments? I don't want to cut this off, but there's nothing sacred about sitting here until 10:00. So for those of you that I cut off to three to five minutes, I apologize. For the rest of you, thank you for your comments and I appreciate your being here this evening.

(Thereupon, the proceedings concluded at 9:00 p.m.)

* * *

This is to certify that I, Debra C. Schmidt, RPR, reported the proceedings in the above-entitled matter, at the time and place hereinbefore mentioned, and that the foregoing pages, numbered 1 through 67 constitute a true and correct record of the stenotype notes taken by me at said proceedings.

Debra C. Schmidt, RPR
Shorthand Reporter
Notary Public
My Commission Expires August 15, 1990

Dated this 16th day of October 1984.

DEBRA C. SCHMIDT
NOTARY PUBLIC -- MINNESOTA
HENNEPIN COUNTY
My commission expires August 15, 1990