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COUNTY, AND MUNICIPAL EMPLOYEES, AFL-CIO

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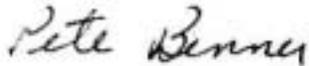
The accompanying Position Paper sets out a proposal from AFSCME, Council 6, regarding Minnesota's care system for the developmentally disabled. This proposal is the result of research conducted from July through October, 1984, on the services for developmentally disabled people that now exist in the state, and projected changes in those services. Three central issues emerge clearly.

1. As privatization has developed in Minnesota, services are increasingly provided by for-profit business corporations. As a result, the state is losing its power to control costs and maintain quality of care. Service delivery is increasingly to the benefit of service providers, and the needs of retarded people are no longer of primary concern.
2. Many of the services now provided in state hospitals do not exist outside of the hospital system. Long waiting lists for many programs, the lack of services for severely retarded people with physical disabilities, and the inadequacy of client contact time forced on county social workers result in chaos for clients embedded in uncoordinated care delivery.
3. The state hospitals, and particularly their staffs, are a valuable resource to the state, a resource that can and should be better used to provide services to developmentally disabled people. Talk of hospital closings and staff layoffs are demoralizing to staff, and threaten to create pools of structural unemployment throughout the state.

Minnesota can address all of these issues: fiscal and quality control, provision of essential services, and maintenance of existing assets in staff and facilities. What is needed is a state-wide, regional system of service delivery. This system will include the state hospitals suitably reorganized, community residential facilities both public and private, and coordinated delivery of other services (day programs, staff training, screening, monitoring, and evaluation) based on the regional resource centers the hospitals can become. Normal life for the developmentally disabled is possible if the state uses its present resources to address the needs of all who are concerned, and initiates strong leadership in developing a progressive policy for the care of our developmentally disabled citizens.

This position paper was prepared by Jacqueline T. Alfonso, M.A., Ph. D. candidate (Philosophy) who has a background of extensive research in areas of social policy, including: 1) food self-sufficiency for Minnesota; 2) problems for women returning to school or the paid labor force; 3) women in science and technology; 4) shelters for battered women; and, 5) communication across disciplines.

Sincerely,



Pete Benner,
Director
AFSCME, Council #6, AFL-CIO

PB/slo

E R R A T A

- Page 17 All Business Concerns (partnership, individuals, business corporations) equal 14%.
Non-profit facilities (including Lake Owasso) contain 1862 beds, 759 of which are licensed Class B. That is, 40% of beds in non-profit facilities are licensed Class B. For-profit facilities containing 3158 beds, have 472 beds licensed as Class B. That is, 14% of beds in for-profit facilities are licensed Class B.
- Page 20 Estimates indicate ... the number of such smaller facilities would increase from the present 320 by more than 800, to approximately 1200.
- Page 26 160 residences are owned and operated by fewer than 66 business corporations. Fourteen (14) business corporations own 96 group homes or 30% of all ICF-MR's.
- Page 27 Host of the Class B community residences for the retarded are geographically concentrated in the Twin City area and Duluth.
- Page 38 The Medicaid Waiver and proposed changes in it are variously interpreted as limiting bed capacity to 6 or 15 residents.
- Page 42 Greenbrier, a private for-profit home, is licensed for 171 beds, all Class A.

SUMMARY

MINNESOTA'S CARE SYSTEM FOR THE DEVELOPMENTALLY DISABLED:

"Developing a system based on need"

POSITION PAPER

AFSCME Council 6

11-19-84

The care system for developmentally disabled people in Minnesota consisted for many years of large state residential hospitals. The past ten years have seen great changes in that system due to the impact of several forces. Social pressure to make the lives of retarded people as normal as possible and to reintegrate retarded people into the larger community has brought about a proliferation of community-based services. Day programs, sheltered workshops, and residential facilities have come into existence in response to that pressure for normalization and deinstitutionalization. But development has been incomplete and inadequate. The result is a policy vacuum, a multiple non-system with little coordination or integration of the many services that now exist.

Federal legislation and judicial action within Minnesota and elsewhere have magnified this pressure by encouraging a move to community-based residential facilities for 15 or fewer residents. Changes in Medicaid policy add to the pressure for smaller facilities without providing for the full range of services that have been available in the state hospital system.

This policy vacuum affects residents of the state hospitals and their families, who see their range of choices of care being whittled away. The lack of a continuum of care and services to developmentally disabled people outside of the hospital system, and the lack of coordination in the services that do exist, are a cause of anxiety even when normalization is the goal.

Minnesota is also losing fiscal and quality control as private, for-profit business corporations move into the present policy vacuum. Some fine attempts have been made at the state level to maintain fiscal control, but increasing privatization and the accompanying lack of coordination make fiscal control more and more tenuous. Quality control also becomes difficult as an already over-burdened county social service system attempts to meet the demands imposed by proliferating for-profit residences and the lack of support services in counties throughout the state.

In addition to the impact on clients and the social service system, deinstitutionalization threatens state hospital employees and the communities in which they live. Thousands of people who are committed to and trained in the care of

developmentally disabled people fear that their lives and their communities will be completely disrupted if the state hospitals are simply shut down with no provision made to reduce that disruption.

AFSCME takes the position that neither perpetuating the state hospital system as now constituted, nor eliminating hospitals entirely, will be the best policy for Minnesota in the long run. The best policy is to develop a systematic, statewide program of care for developmentally disabled people. Such a system will include hospitals, state-owned and operated intermediate facilities and smaller group homes and semi-independent living situations, as well as privately owned and operated facilities. Such a state-initiated, state-monitored program will retrieve fiscal control at the state level, control which is absent in the present agencies and foster homes. A creative solution to fiscal and social problems is needed, a vision for the future that will give long-term stability and ensure quality of care for Minnesota's developmentally disabled people.

The problems in the present non-system are many and varied:

- 1) Private, for-profit facilities have "skimmed" clients, either by refusing to serve all but the easiest clients, or by rigidly specializing so that residents are segregated according to their disabilities.
- 2) The public dollars spent on care delivery go to profits rather than to improving care. In some private residences, training and experience in caring for developmentally disabled people count against prospective employees. Training is not uniformly available and often is not encouraged by owners. Staffing is often minimal and turnover is high, due to the push to increase profits. More subtly, the way the work is viewed changes when profits, not the best care, is the goal.
- 3) Monitoring and evaluation of care become increasingly difficult as privatization develops. Access to facilities and systematic procedures to address problems are far less likely when care delivery is private.

- 4) Continuity, so important to developmentally disabled people, becomes problematic when business corporations control care delivery. The problems Minnesota has seen with the privatization of nursing homes and health care delivery are examples of what we can expect with increasing privatization of services for retarded people.
- 5) Decentralization and normalization, the goals and motivation of change, have not happened. Private facilities for large numbers of residents are no less institutions than state hospitals. Ghettoization also occurred, with most of the private residences located in urban areas, and concentrated in a few neighborhoods within those urban areas.
- 6) Consistency of care throughout the state cannot exist without coherent policy at the state level.

What Minnesota needs is a care system for developmentally disabled people that is uniform and coherent, a system which will include smaller facilities where that is of benefit to residents. At the same time, such a system must not waste present state investments in staff and buildings. This is particularly true when those investments can be used wisely to provide a cost effective, coordinated care delivery system.

AFSCME proposes that Minnesota develop such a system on a state-wide level, using present hospitals as regional hubs for a full continuum of services. The regional networks will include the present hospitals, gradually reorganized as resource centers and residences, state-owned and operated community residences, private community residences, Day Activity Centers, and other day programs and services. Present hospitals can provide: long-term care for some residents; screening, evaluation and program development; coordination of placement into community facilities; regional coordination of specialized equipment, staff expertise and training; and overall monitoring and evaluation for the system as a whole.

In such a system, clients and their families will be assured of quality care and continuity, as well as access to and clear-cut mechanisms for addressing problems. The state will be able to maintain fiscal and quality control, and be assured of consistency of programs and training on a state-wide basis. Counties

will benefit by the increased residential and day program options offered by the state.

In addition, the economic health of hospital communities will not be jeopardized. Staff will be assured of a gradual transition and the present investment in staff will not be lost to the state.

Minnesota can foster regional economic development, rather than creating structural unemployment in hospital communities. Buildings, services, and equipment can be used to provide services so desperately needed, such as respite care, crisis intervention, and training and program options.

Minnesota has an opportunity to develop a care system for our developmentally disabled citizens that is progressive, thoughtful, and that maintains fiscal and quality control. We can maintain and develop assets in bricks and mortar, and assets in people who are well-trained and committed to working in a care system for developmentally disabled people. All of these goals can be met by developing a state-initiated and state-operated regional system of circles of care for developmentally disabled people in Minnesota.

MINNESOTA'S CARE SYSTEM FOR THE DEVELOPMENTALLY DISABLED:

POSITION PAPER

"Developing a system based on need"

AFSCME Council 6

11-19-84



This position paper was developed by an independent research consultant engaged by AFSCME Council 6 to review background and data on programs for the developmentally disabled in Minnesota. Research included:

1. Literature survey;
2. Interviews with AFSCME members who work in state hospitals;
3. Interviews with county social workers;
4. Interviews with staff in group homes;
5. Interviews with advocates and parents of developmentally disabled people living in state hospitals and private group homes;
6. Employment interviews with private for-profit group homes; and,
7. Study of business corporations providing services to developmentally disabled people in Minnesota.

* * * * *

The position paper discusses the present care provided for developmentally disabled people in Minnesota, and suggests a creative approach to a future system. This approach takes into account the needs of clients, the need for the state to maintain fiscal and quality control, and the need to foster rather than hinder economic development throughout the state. The focus of the report is on:

1. The nature of the care system, both now and in the future;
2. The costs of a care system, both fiscal and social; and,
3. The level of care necessary for the retarded people in Minnesota, the primary concern.

Minnesota is in an exciting time of change in state policies that address the needs of our developmentally disabled citizens. All of the factors are present that will enable us to shape a progressive, thoughtful, and comprehensive policy for the future. The Minnesota Legislature is actively involved due to past legislation, court rulings, and the impact of national policies. Families of developmentally disabled people are involved in large numbers. Some are concerned because there is no clear, long-term policy and they are worried about instability in the lives of their loved ones who are embedded in the present non-system. Some families are concerned because they are eager to provide the most normal environment possible for their disabled family members. Employees are concerned, especially those in the state hospitals, in part because their jobs and their own families are threatened when there is discussion about dismantling the entire system. Just as importantly, employees in hospitals and throughout the state in group homes are worried that the people they care for are being lost in the shuffle, forgotten in fiscal and ideological debates. As a result of employee concerns, whole towns and the State Employees' Union are involved in policy issues as well. All of these parties, legislature, families, employees, towns, and union, are concerned to forge a reasonable, coherent, and fiscally responsible system of care for Minnesota's developmentally disabled people.

In addition to the thousands of people actively concerned with the present and future of Minnesota's retarded citizens, research has shown that "deinstitutionalization" (removing people from large state institutions and placing them in smaller environments) suffers from the "lack of a systematic or integrated approach to the improvement of programs for developmentally disabled persons."¹

Times of change, as in the case of changes in how Minnesota provides for our vulnerable retarded citizens, offer unique opportunities to formulate coherent, fiscally sound, and socially progressive solutions to policy issues. This report

¹ Wieck, C.A., and Bruninks, R.H., "The Cost of Public and Community Residential Care for Mentally Retarded People in the U.S.", Developmental Disabilities Project on Residential Services and Community Adjustment. Dept. of Psychoeducational Studies, U of M, Minneapolis, 1980. Citing Blett, Bogden, Biciclen, and Taylor, "From institution to community: a conversion model," Syracuse University MS 1976.

presents a case for a state-wide, systematic continuum of care for Minnesota's developmentally disabled population. A state-initiated system, consisting of a state-wide network of state coordinated, publicly and privately operated residences, ranging from foster homes to large institutions, and other services is the best method to provide fiscal control, accountability, a consistent program of care, and to take account of the legal and social interests of all the parties involved.

AFSCME'S POSITION

AFSCME takes the position that neither perpetuating the state hospital system as now constituted, nor eliminating hospitals entirely, will be the best policy for Minnesota in the long run. The best policy is to develop a systematic, statewide program of care for developmentally disabled people. Such a system will include hospitals, state-owned and operated intermediate facilities, and smaller group homes and semi-independent living situations, as well as the present privately owned and operated facilities, and direct assistance to families. Such a statewide, state-monitored program will restore fiscal control at the state level, control which is absent in the present amalgam of state-subsidized for-profit community residences, non-profit agencies, and foster homes. A creative solution to fiscal and social problems is needed, a vision for the future that will give long-term stability and ensure quality care for Minnesota's developmentally disabled people.

Other states have experienced grave problems when deinstitutionalization has been hasty or thoughtless. When beds rather than client needs are the criteria for placement, chaos and scandal have resulted. Ohio has placed people in private group homes where neither staff nor administration is properly trained. Diets of celery and crackers, filthy living conditions, and questionable ethics among owners of private facilities have been some results. Yet we know that deinstitutionalization can be done well. Rhode Island offers a superior model for regional organization in Minnesota. The size of Rhode Island's program will easily translate to a regional network for Minnesota.

The state hospitals, with their large, long-term investment in buildings and staff, are well suited to be hubs for a state-wide, integrated system. The

existing state hospitals are geographically placed to become regional centers in a network of state-owned group homes, semi-independent living facilities, and other resources for retarded persons and their families. A state-owned and operated component in the system will make the best use of present state investments in buildings and staff. Resources exist for screening residents, placing people appropriately, arranging and developing programs for residents, and evaluating results. All of these resources can be upgraded and improved, returning the focus to the needs of clients and away from top-heavy administration. Present hospital facilities can serve as respite-care centers, as emergency housing for retarded people who need it, and as long-term residences for the most difficult cases and for those retarded people for whom the larger setting is appropriate.

The staff of the hospitals is a skilled but under-utilized pool of expertise for staff of other facilities, both public and private. As linkages between the hospitals and other facilities, particularly when residents move out of the hospital setting, hospital staff could provide exactly the sense of continuity so essential both to developmentally disabled people and to a coherent system of care. In a coordinated state-operated system, the field of vision of hospital staff will be regional. Because of their location, the hospitals can serve as regional training centers for staff in other facilities, gaining input from the larger community. In addition to screening and placement of residents, hospital staff can provide outreach services to the larger community, making specialized staff and equipment available region-wide. Duplication of services and under-utilization of services will be avoided.

As screening facilities, hospitals should be at the center of a network of developing programs throughout the state. In a systematic care program, each resident could be screened, placed appropriately, provided with programs for future development, and followed throughout the system and over time. Flexibility and mobility within the system would be enhanced; neither is now present in Minnesota's programs for developmentally disabled people. At present, residents are removed from hospitals by fiat, whether or not that move is appropriate, and only those people can be placed for whom a bed is available elsewhere; the decision is based on beds, not what is right for a given person.

"What am I going to do when I can't place a client in a hospital and the client gets demitted from a [community] placement?"

(A Ramsey County Social Worker)

In addition, residents are lost to the monitoring system within 30-60 days. If they don't do well in group homes, residents may again go through lengthy and expensive court proceedings to be admitted to hospitals. Little coordination is present between the hospitals and other residences, and is in fact resisted in many cases by group home administrators. Present care delivery quarantines public and private programs away from each other. This situation must be altered if clients are to receive the best care possible, and only a public system can eliminate those barriers to cooperation.

Hospital facilities are similarly appropriate as regional training centers for staff in other parts of the system. Adequate training outside the hospitals, even if available, is sometimes resisted by owners of for-profit homes.

"You don't have any training? Fine....I don't want someone coming in here telling me how to run my business."

(Owner of a private, for-profit group home)

As a result, retarded people are being warehoused in smaller settings just as they once were in hospitals. Underpaid staff with little or no training cannot provide necessary care. A state system that is a mix of public and private facilities can make training available throughout the state.

As the population of residents within the hospital system declines, as it surely will, job security will be maintained for staff who move within the state system, out of large institutional facilities and into regional residential facilities. Years of training and expertise will not be lost to the state economy, and staff can maintain important working relationships with residents and other staff². Transfer of staff within a state-owned and operated system of residences will be smooth,

² Preventing the loss of a valuable labor pool and maintaining continuity for residents has been a major consideration in Rhode Island and New York (cf. State of New York, "Implementation of Major Mental Hygiene Initiatives [Morgado].")

voluntary, and strengthen the network, since communication is already present among the employees, staffing procedures exist, and morale will be maintained among staff.

Monitoring the costs will be made easier and quality of care will be improved by a secondary level of direct monitoring in each region, A network of group homes, foster-care homes, semi-independent living facilities, and workshops and activity centers will exist as facets of an integrated system, with the present hospitals, gradually altered, at the hub. Flexibility across the system is facilitated, since the system functions as a whole. Long-term residents and the general population to be screened can move into whatever residential facilities are appropriate. Their progress can be monitored and when one setting is found not to be advantageous, another can be utilized. Hasty changes can only result in chaos for clients and confusion in the delivery of care. Retraining and the development of effective programs take time, if we take retarded people and their circumstances seriously.

AFSCME advocates developing a regional system as the best way for Minnesota to accommodate our developmentally disabled population. The private sector is not responding to the needs for facilities for severely handicapped people. A segregated structure has come into existence, with the least disabled people residing in group homes run for profit, where quality of care is extremely difficult to assess, while the most disabled people are left in the state hospitals or non-profit residences. Mandated depopulation of state hospitals has meant that numbers of beds in the community have become more important than whether or not a community setting is right for a given individual. There are 40-50 residents in Cambridge State Hospital right now who are supposed to be in the community, but for whom there is no space.

There is a radical anti-institution position, with small but vocal support in Minnesota, that maintains that all retarded persons should be with their birth families or in foster homes. It is simply not possible for many families, whatever they might want to do, to provide adequate care for their retarded family members. Monitoring is impossible for the number of foster homes that would be required; the potential for abuse is enormous.

Recent legal decisions hold that when a state is forced by circumstances into acting as a parent, adequate professional judgment regarding appropriate placement should be the determining factor. A narrow interpretation of legitimate concerns for constitutional rights to a "least restrictive environment"³ has meant that a mechanical quota system of placement has taken hold in Minnesota. Anti-institutionists advocate "family-type" living arrangements under a very narrow interpretation of "family", and push for small housing facilities that may be more restrictive for residents than larger facilities.

A state-initiated, mixed system of public and private facilities and services will return the focus of care to the real needs of clients. Placement can be based on client needs rather than quotas. Families and advocates will have access to the system so that it can be continually improved. This problem can be seen clearly in present care delivery. Public institutions have responded to complaints and have improved steadily over time. There is still room for improvement, but the momentum and mechanisms to do so exist. Private facilities, on the other hand, have failed to show similar progress.

The same complaints about private facilities are made over and over again to the Health Department and other agencies. There is no coordination and no assurance that complaints brought against one facility will be addressed by others. Privatization has not led to greater access for families and advocates, and has not been responsive to their legitimate concerns. Only a publicly organized system of care delivery can provide that needed access and responsiveness.

Parents and families of developmentally disabled people who are now in state hospitals have demonstrated great confidence in state-operated services. Recent town meetings throughout the state are evidence of that confidence. Parents have access to decision-making procedures, clearly articulated grievance procedures, and opportunity to influence the care and programs for their children in a state-operated system. There is no guarantee that any of this access would be available in a purely private system, no insurance that a private system would be responsive to parents' concerns. The speed and accuracy of

³ U.S. Court of Appeals for the Second Circuit, Docket Nos. 83-7621, 6/13/84, Suffolk Co., N.Y.

present procedures can be improved; they are not perfect. Yet complaints are addressed in the hospital system, and procedures can be expanded to state-operated community facilities.

It is not AFSCME's position that the state hospitals, as now constituted, should be maintained. The hospitals represent a significant investment to the state that can be reorganized to make the most effective use of that investment. The state hospitals can be decentralized slowly, maintaining wherever possible state services and jobs. Problems in the current care system for developmentally disabled people can be addressed by redefined and reorganized state resources. For example:

- a) Larger counties (Ramsey, Hennepin, St. Louis) have long waiting lists for client services. We need to expand available residential and day program options, and state-developed, state-operated services can address this need.
- b) The use of state social workers as case managers for a cluster of group homes would provide monitoring at the regional level and consistency across the system.
- c) Line staff would be available for trained crisis intervention in public and private facilities. Residents in crisis would not need outplacement in expensive medical facilities in a crisis, if trained staff can be brought in.
- d) Hospitals and private or public residential facilities would no longer be quarantined from each other, but integrated and coordinated.

A balanced system of state-owned and operated services together with private facilities puts the needs of clients first. Appropriate placement, whether public or private, can be provided when there is a broad spectrum of care delivery.

What is the vision for the future?

Imagine first, a young girl who is developmentally disabled and who lives with her birth family in New Prague. She attends a Day Activity Center, with other children who live at home or in a local group home for retarded people.

The Day Activity Center makes use of equipment, programs, and staff from Faribault State Hospital. The girl's family can use the resources of the hospital when needed: specialized medical and dental care, help with behavior training and developing in-home programs so that she moves ahead as well as she can. She and her family are familiar with hospital staff and with staff at the local group home, also operated by the state. As her family ages and becomes less able to care for her, arrangements are made for her to move into the group home. That transition is easy for everyone. Continuity is maintained in daily life and in the young woman's development. The group home uses the same hospital facilities, so the woman's medical care and program development don't alter for her. The group home, owned and operated by the state, has been in place and will continue to be there; the woman's family doesn't need to worry that she will have nowhere to go when they can't advocate for her. The home will not close because its profits are insufficient, as other private health care agencies have closed.

Imagine another case, a small child with multiple physical and developmental handicaps. His family simply cannot provide the care and equipment necessary for his life. Professional screening and examination of community resources indicate that only the regional hospital can accommodate him adequately. While in the hospital, access to therapy and medical care result in a dramatic improvement in his situation, and with some of the enriched services that the hospital can provide to a local group home, he is moved there, where he is closer to his family. Contact is maintained with hospital staff through the services provided to the group home for his benefit, transportation and mobility equipment, and a weekly visit by a physical therapist, who trains local staff in how to aid him. He does well for a time in the group home, but then begins to become more debilitated and is returned to the hospital. Over a period of time a pattern emerges: this young man does well in the group home for six or eight months, and then needs some time, a few weeks, in the hospital. Since there is continuity of staff and programs, this pattern can be met by the system of care. The young man can be in a small group home and near his family, but when he requires time and more elaborate equipment and care than can be provided there, he spends some time in the hospital. There is minimal trauma for him since there is staff continuity, and developmental programs are consistent, since staff in the hospital and group home are in communication with each other. In time, he may need

to be in the hospital permanently, but until that is necessary, this young man can live in a home-like environment, near his family.

These are both visions of a future we can build. What is the reality now?

PRESENT CARE DELIVERY

The present care system for retarded people in Minnesota consists of many, varied, and uncoordinated services. Much of the state hospital system is still in place, although drastically altered in the past ten years. In addition, smaller residences have sprung up, housing from 1 to 64 people. There is ample evidence that most retarded people {up to 90%} live with their birth families, as they always have. Many are in nursing homes. (DPW data indicated in 1982 that 300 people in nursing homes were retarded; anecdotal information puts the number much higher.)

TYPES OF FACILITIES

Residential facilities are characterized by the type of care provided.

1. Foster homes are small, housing no more than 5 non-family members. Residents may have any type of disability from mild retardation to severe physical and developmental disabilities. Care may range from 24-hour supervision to bed-and-board.
2. Community Intermediate Care Facilities (ICF-MR) may house 6-170 people. There is 24-hour staff, either shift workers or houseparents with weekend relief. Residents may have any type of disability, although by far the greatest number are ambulatory, toilet-trained, and can feed and clothe themselves.
3. Semi-Independent Living Situations (SILS) are housing units for residents who can largely care for themselves. Private rooms or apartments and staff are provided for residents, who may work at a job, in a sheltered workshop, or participate in other day programs.
4. Supervised Living Arrangements (SLA's) resemble ICF-MR facilities, but with less intensive care provided. Staff-to-resident ratios are also lower.

These four categories are all "Community Residential Facilities". Institutional facilities include the eight state hospitals, Cambridge and Faribault State Hospitals house only retarded people; Brainerd, Fergus Falls, St. Peter, Moose Lake, and Willmar have programs for retarded people, and also for mentally ill and chemically dependent people. Anoka serves the mentally ill and chemically dependent,

DEINSTITUTIONALIZATION HAS FAILED IN ITS GOALS

"Deinstitutionalization" is the name for the process of moving people from large institutional settings into smaller community residences. The concept arose out of widespread reaction to conditions in some public institutions, where residents were warehoused in large wards with little or no developmental programming. Horror stories about a few institutions where residents spent most of their time milling around naked, or about people mistakenly labeled retarded and left to languish for years in state hospitals provided nationwide impetus for change. Changing views about civil rights and active advocacy on the part of the reformers led to changed public policies regarding developmentally disabled people. The result has been an effort to provide developmental programs and smaller, family-like living environments for retarded people. The goal has been to provide movement through the system and beyond for those who can progress, and to give appropriate support for those who cannot move beyond the care system.

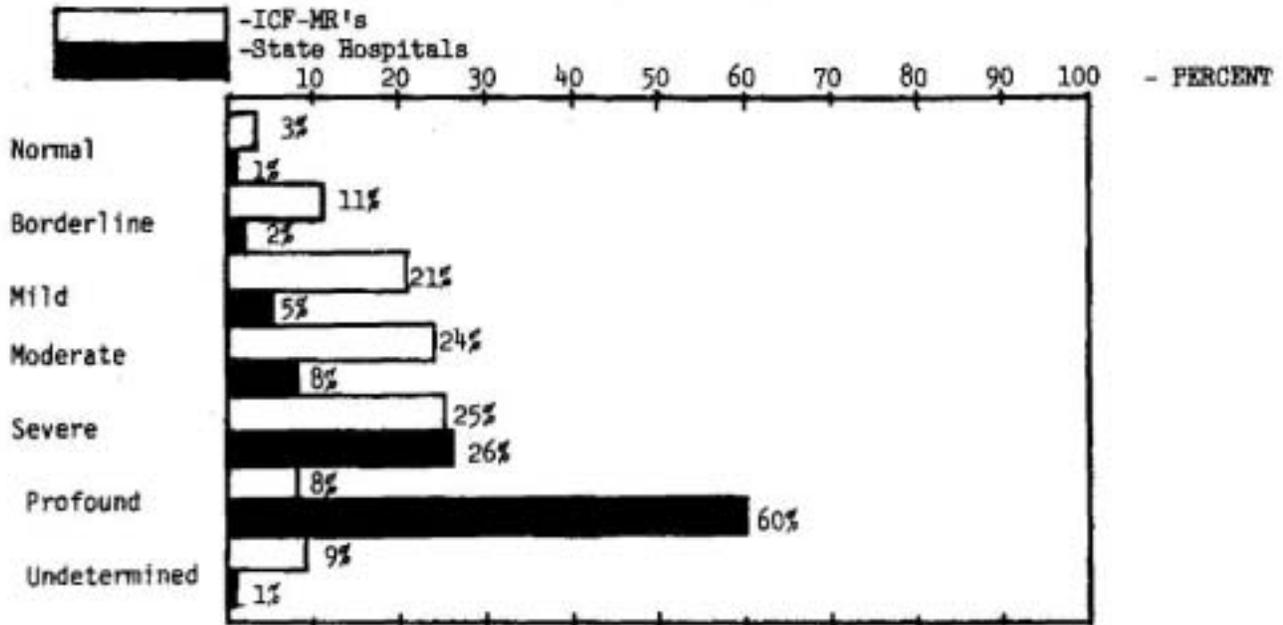
At the same time, simply moving people was seen as an inadequate change and efforts were begun to ensure that the lives of retarded people were as normal as possible. The most radical advocates of "normalization" argue that all developmentally disabled people should be with their birth families and in those families' communities. A more moderate approach has called for small residential facilities where life for retarded people can be as normal as possible. Schools have incorporated special programs, Day Activity Centers have been developed, and sheltered workshops and job training and other habilitation programs have been proliferated.

Both deinstitutionalization and normalization have had enormous impacts on large public residential facilities. The population of state hospitals has been reduced and hospital programs and procedures have changed dramatically.

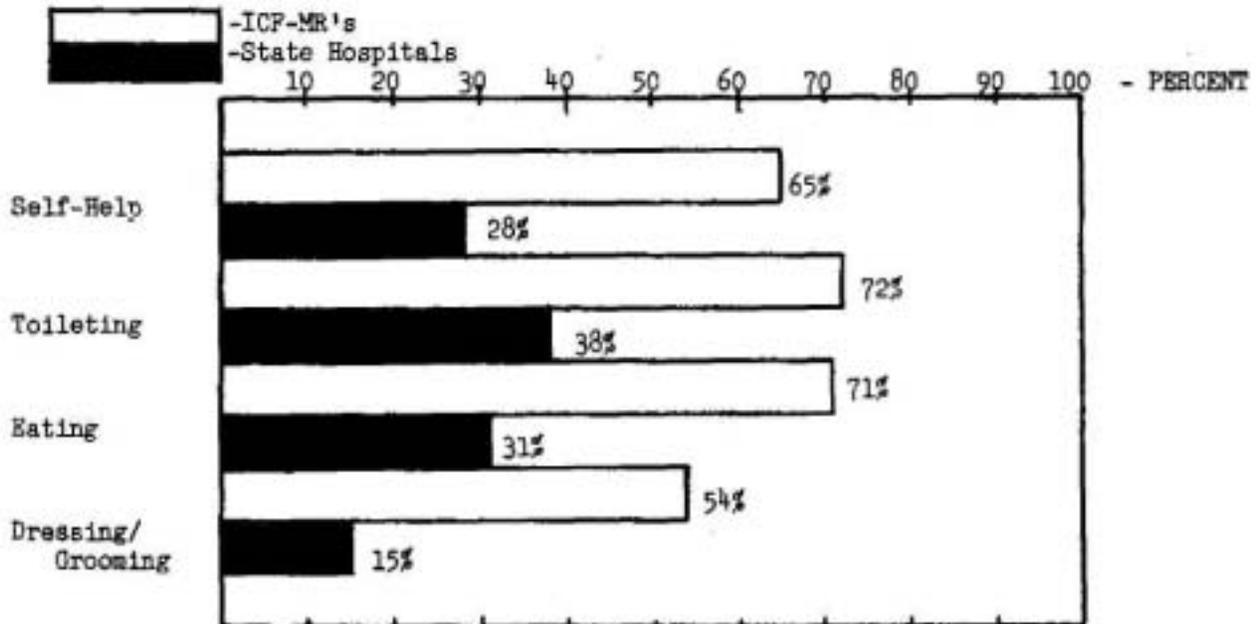
Increasingly, smaller living units have been developed within the hospital structure. Private residential facilities, 321 in Minnesota, have also come into existence.

Due to the way deinstitutionalization has been carried out in Minnesota, residents have been segregated according to disability. The least disabled people are in the community, whether in foster homes, SILS, SLA's, ICF-MR, or with their birth families. The most severely disabled are still in hospitals or in non-profit facilities (because many private vendors have refused to admit them).

RETARDATION LEVELS IN STATE HOSPITALS AND
PRESENT COMMUNITY ICF-MR FACILITIES



INDEPENDENCE LEVEL OF MR POPULATION IN HOSPITALS
AND PRESENT COMMUNITY ICF-MR FACILITIES



Facilities are licensed according to whether or not they can accommodate residents who are ambulatory and capable of self-preservation. Class A facilities, for example, house people who are able to leave on their own in a fire; Class B facilities house those who cannot.

TYPE OF FACILITY		NUMBER OF RESIDENTS
Public		(licensed capacity)
<hr/> 8 State Hospitals:		
	Class A	
	Class B	2,250
1 ICF-MR:		
	Class A	
(Lake Owasso)	Class B	64
TOTAL PUBLIC FACILITIES : 9		
<hr/> Non-Profit		
142 Facilities:		
	Class A	1,103
	Class B	695
<hr/> For Profit		
179 Facilities:		
	Class A	2,686
	Class B	472
TOTAL COMMUNITY FACILITIES: 322		
	Class A	3,789
	Class B	1,167

Private for-profit facilities have concentrated on clients who are the easiest and cheapest to serve to a remarkable degree; non-profits have shown greater response to the need for Class B facilities. This is a structural defect in present care delivery, and cannot be resolved by hand-waving or promises of future change.

CENTRAL ISSUES IN CARE DELIVERY

Abundant rhetoric on all sides of the deinstitutionalization issue has concentrated on the following broad areas:

Cost: How much can we pay, how much are we willing to pay, for the care of developmentally disabled people? Where will the money come from?

Level of Care: What are the real needs of developmentally disabled people? When is normalization beneficial, and when is it harmful?

Nature of the Care System: How shall we address the needs of retarded people? What role do private enterprise and federal, state, or county governments have in a care system? How should a care system be structured?

A careful examination of each of these areas of concern will reveal the nature and extent of the problems yet to be faced, and suggest a solution, a state-wide, state-initiated, broad spectrum of care, which will most effectively address these concerns.

Affecting the problems and the solutions in a major way are several external pressures, among them nationwide trends to relegate public social services to private, for-profit vendors, the Medicaid Waiver System, and the Welsch v. Levine consent decree. Each will be examined in turn. The solution? "AFSCME agrees with the preponderance of professional opinion that a balanced service system, characterized by a continuum of care, will best meet the needs of developmentally disabled individuals. This continuum should include high quality institutional and community-based services which meet the specific medical, habilitation, educational, training, leisure-time, and protective needs of developmentally disabled people."⁴

An integrated, flexible system of care, organized and operated at the state level, with present hospitals serving as a secondary level of organization,

⁴ American Federation of State, County, and Municipal Employees (International), Mental Health and Mental Retardation Policy, AFSCME, 1984.

will provide such a continuum of care. As regional centers for a network of state-operated group homes and other residential and non-residential services, the hospitals will make the best use of present staff and capital investments and provide essential control of costs and quality.

COST

The discussion of a care system for developmentally disabled people in Minnesota has for some time assumed that smaller is less costly. This assumption is not justified on examination; too much is left out. As Mayeda and Wai found, "Community placements are not less costly than institutional care when all required services are provided, and...significant cost 'savings' only appear when specialized services are not provided, unavailable, or under-utilized... (and) the likelihood is strong that the cost-effectiveness of services will vary among subpopulations of the mentally retarded who require out-of-home care..."⁵

Data from Michigan shows a disparity in costs according to client disability: per diem rates for community facilities are set according to the disability level of residents and costs are higher for more disabled clients. The state relies heavily on community services to provide what was once available in state hospitals.

When costs are compared among the types of residential services for the retarded available, flat per diem costs of the services are most often considered. This sort of comparison indicates that the state hospitals are far more expensive than other residential settings. However, when all costs are counted, the hospitals are within the range of per diem rates for ICF-MR. For example, a 1982 report on community services for the mentally retarded shows the following rates:⁶

⁵ Mayeda, T., and Wai, F., "The cost of long term developmental disabilities care.", Pomona, UCLA Neuropsychiatric Institute, 1975.

⁶ Program Evaluation Division, Office of the Legislature Auditor, State of Minnesota. "Community Services for the Mentally Retarded," 6/2/82.

<u>STATE HOSPITALS</u>	<u>COMMUNITY</u>	<u>ICF-MR</u>
	<u>Adult</u>	<u>Child</u>
\$60.35	\$39.00	\$39.00

But these are costs for residential services only. On the next page of the same report are the following costs for developmental services:

<u>STATE HOSPITALS</u>	<u>COMMUNITY</u>	<u>ICF-MR</u>
	<u>Adult</u>	<u>Child</u>
\$10.65 (already counted in the \$60.35 above)	\$22.00	\$32.50

What this indicates is that when both residential and developmental services are counted, the rates are as follows:

<u>STATE HOSPITALS</u>	<u>COMMUNITY</u>	<u>ICF-MR</u>
	<u>Adult</u>	<u>Child</u>
\$60.35	\$61.00	\$71.50

This data demonstrates that the cost differences between public and private facilities are not as great as some claim. There is no breakdown of rates according to disability level, and we know that many of the most difficult, and therefore most expensive clients to care for are in public facilities. Moving from a public to a private system as a cost-cutting measure is not justified when actual costs are considered.

COST FACTORS IN A CARE SYSTEM

A recent study concludes, "The variables producing statistically significant variations in per diem rates were: 1) staff to resident ratio; 2) proportion of residents who are non-ambulatory; 3) number of years in operation; 4) age of residents; 5) profit/non-profit status; 6) facility size, 7) family owned and operated facilities; and, 8) licensed capacity."⁷

1. Staff to Resident Ratio:

Staff to resident ratios in facilities serving developmentally disabled people should be directly related to the dependency levels of the resident population⁸. Residents who are not toilet-trained, cannot feed or cloth themselves,

⁷ Developmental Disabilities Program, Dept. of Energy, Planning, and Development, State of Minnesota. "Policy Analysis Series #4: Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems. St. Paul, 9/30/81.

⁸ *ibid*

who exhibit aggressive or violent behavior, or who require extensive nursing, obviously require more staff than residents who feed and clothe themselves, are toilet-trained, and are otherwise healthy and amiable. At present, fewer than one-third of the beds in "small" residential facilities in Minnesota are licensed for residents who lack self-preservation skills or who are not ambulatory, all of whom require a high ratio of staff to residents. Of those residences which are so licensed, less than one-third are for fewer than 15 people. There is only one group home in the state that accepts residents who require restraint, and that is a county facility.

The more serious the disabilities of residents, the higher the ratio of staff to residents, even when residents are ambulatory. Small, residential facilities show a lower per diem cost per resident in part because they serve the least disabled clients or a higher specialized group of clients. This is particularly noticeable in the differences in license status between non-profit providers and facilities operated for profit.

Percentage of Beds Licensed Class 6, By Ownership Status:

Public.....	100%
Non-Profit (Religious Affiliation)...	31%
Non-Profit	31%
Partnership	14%
Individual	0%
Business Corporation	15%
All Business Concerns (partnership, individual, business corporation)...	30%

Non-profit facilities contain 1,798 beds, 759 of which are licensed Class 8 (40%), while facilities run for a profit, containing 3,158 beds, have only 472 beds licensed as Class B (14%)⁹ Class B certification relates to medical problems primarily, not behavior problems. Private for-profit providers have consistently refused to care for residents with even mild behavior problems. As one Ramsey County Social Worker said, "one of my clients was evicted from a group home because of 'behavior problems'. His 'behavior problem'? He taps his nose

⁹ American Federation of State, County, and Municipal Employees, Council 6, 1983.

with his palm!" This selectivity in service is known within the system as "creaming", that is, skimming only the "cream", residents who are amiable, easy to deal with, who require little supervision and therefore smaller staffs, or who match a specialized service. The definitions and practices are based on the interests of providers rather than the needs of clients. The state hospital system cannot be selective about who is served. It would be an error to consider flat per diem rates without taking this selectivity into account.

Obviously, a high staff to resident ratio is more costly than a low staff to resident ratio. Just as obviously, those ratios are directly related to the level of care required by a resident population. As a parent of a hospital resident said,

"My son is 9...severely retarded, cerebral palsied, and has a hearing loss.... Severe and profound or medically fragile people need so many special things--equipment for eating, sitting properly, vans for transporting wheel-chairs, access to therapy, nursing 24 hours a day....I really don't think a small home could even be economically as efficient as a larger facility, if that's what people are worried about."

The issue presented by this parent is not one of size, but of what isn't being provided in the community, and of where the costs are borne. Per diem rates in hospitals do not compare with per diem rates in group homes, since many specialized services are funded in the community settings through other means than per diem costs. However, the state has many of these resources available, or could obtain them for smaller residences in a cost effective manner, since duplication and under-utilization could be avoided with state coordination. Therapy, transportation, and medical care are the types of services the hospitals could offer as part of a network. When expensive specialized services can be offered out of a regional location to group homes throughout the state, those group homes will be able to care for a wider range of residents. This will be cost-effective. In addition, the segregation of residents by level of disability can be avoided.

2. Proportion of Residents Who Are Non-Ambulatory:

"The mean per diem rate for ... Class B facilities was 36% higher than for ... Class A facilities. Class B facilities were larger and their staff-resident ratios were higher."

"There is no advantage to being located in a small home in a community...if an individual is so severely retarded that he cannot cross the street...if an individual is severely retarded and cannot do the things that [a] less retarded individual can do, the advantages provided by a large setting are extremely important."

(A Parent)

"I cannot believe that such an assortment of staff persons is likely to be assembled in one small geographical area in the community in the foreseeable future (one-to-one staff person, daily care aides, social worker, nurse, doctor, psychologist, DAC teacher, physical therapist, etc.)."

(A Parent)

Most of the developmentally disabled people with multiple problems are in large settings, including state hospitals. For these people, the services they require do not exist in the community, and will be costly if they are provided. The state has the staff and equipment to develop needed facilities. Using the state hospitals and state staff as a resource base is one way to control costs for specialized care.

Among the developmentally disabled people in Minnesota, 34% have physical handicaps, 24% are not toilet-trained, 16% cannot feed themselves, 10% are not ambulatory, and 8% are bed-ridden. Many of those people with multiple problems are in large institutions, including state hospitals. Most of the early wave of "deinstitutionalization" placed mildly retarded people in community settings; a very high proportion of the present population in the hospitals consists of people who are severely or profoundly retarded and who have other physical problems as well.

Developmental Disabilities Program, Policy Analysis Series #15.

"What does it mean to 'monitor outcomes' when the outcomes are so small there's no way to monitor? What about a client whose program goal for five years is to get him to raise his hand six inches when you tell him it's time to get dressed?"

(A Hennepin County Social Worker)

Estimates indicate that if the population of developmentally disabled people now institutionalized were relocated into "family size" facilities, the number of such smaller facilities would increase to approximately 1200¹¹. According to some DHS staff, 99% of the places in those 880 new facilities would need to be able to care for severely and/or multiple-handicapped residents in order to accommodate the people now in the hospital system. A moment's reflection should make it clear that expensive and highly specialized services, which are not now available in smaller residences, will dramatically increase the per diem costs of those residences. Fewer than one-third of the beds outside the state hospital system now accommodate more difficult cases. Those facilities that are licensed for non-ambulatory and Class B residents tend to be non-profit, larger (up to 64 residents), and have a higher per diem than residences licensed Class A.

3. Number of Years in Operation:

Costs are higher in new residential facilities than in established facilities¹². This is due in part to capital costs relating to construction, startup, and to staffing. Arguing that cost differentials are merely transition-era "bulges" may be a mistake, however. In fact, there is wide disparity between proposed per diem rates of new facilities and the rates eventually settled on. As the chart on the next page indicates, the average increase from proposed rates to final rates is 38%¹³.

¹¹ Citizens League Report, "Meeting the Crisis in Institutional Care: Toward Better Choices, Financing and Results", Minneapolis, Citizens League, 4/25/84.

¹² Developmental Disabilities Program. Policy Analysis Series #4, St. Paul, 9/30/81.

¹³ Program Evaluation Division, Office of the Legislative Auditor, State of Minnesota, "Evaluation of Community Residential Programs for Mentally Retarded Persons." St. Paul, 2/11/83.

This data led to tightening up the reimbursement mechanisms. The potential for fiscal abuse is clearly a major concern in Minnesota as privatization has increased.

COMPARISON OF PROPOSED, INTERIM, AND SETTLE-UP
RATES FOR FACILITIES OPENED IN 1981

FACILITY	(1) Proposed Per Diem Rate (CON/§1122)	(2) Interim Per Diem Rate (Rule 52)	(3) Settle-Up Per Diem Rate (Rule 52)	Percent Increase (3)-(1)	Percent Increase (3)-(2)
Caromin-Two Harbors	\$ 33.66	\$ 41.92	\$ 56.05	66.5%	33.7%
Oak Ridge-Aitkin	33.54	37.58	48.18	43.6	28.2
Charis House-Brainerd	47.37	46.53	58.70	23.9	26.1
Swift County Group Home	33.23	40.76	47.91	44.2	18.3
Opportunity Manor-St. Cloud	41.17	46.10	46.41	12.7	0.7
REM-St. Cloud	NA	63.78	*	NA	NA
Residential Alternatives VI	43.05	42.01	60.69	41.0	44.5
Elm Residence	46.78	51.86	61.26	31.0	18.1
Hiawatha Adult Home	45.50	77.31	*	NA	NA
ACR Cummins	58.71	60.51	68.50	16.6	13.2
Good Neighbor-Edmund	51.01	57.05	62.63	22.7	9.8
Logan	74.32	74.32	81.57	9.7	9.7
Minnesota Jewish Group II	49.44	49.44	*	NA	NA
Nekton-Hodgson	58.57	58.57	*	NA	NA
NE Respite Care	35.38	57.95	70.94	100.5	22.4
Oakwood Residence	66.31	60.93	*	NA	NA
REM-Bloomington	NA	64.19	*	NA	NA
REM-Minnetonka	35.61	69.89	*	NA	NA
Residential Alternatives VIII	48.64	48.36	*	NA	NA
The Woodlands-Orono	72.02	72.02	103.75	44.0	44.0
				Average Increase = 38.0%	Average Increase = 22.4%

Sources: Rule 52 Cost Reports—Department of Public Welfare
§1122 and Certificate of Need Files—Department of Energy,
Planning, and Development, Minnesota Department of
Health.

Notes: *-Final rate not yet established as of December 27, 1982. NA-
Not Available.

New facilities must be increasingly specialized to serve a more severely disabled population. Past experience gives little indication of future costs, except that they will be higher. The resource base of the hospitals, including staff trained to work with this population, as well as equipment and services, provides a starting point for a public, systematic approach to care.

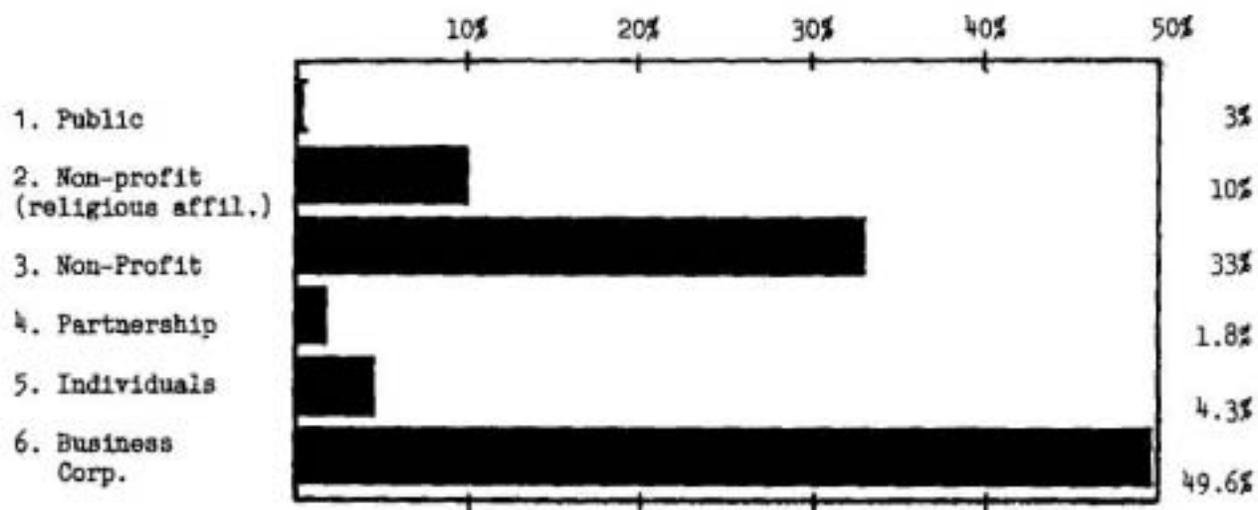
Most of Minnesota's present residential facilities are operated for profit. Given the natural tendency of business corporations to maximize profits, present data on costs over time may not hold in the future. And what will be the nature of a transition era bulge if, as some suggest, 880 new residences, all serving severely and multiply-handicapped people, must be operating within the next five to seven years? Minnesota will be caught up in a spiral of costs over which the state has little or no control. One clear alternative is for the state to regain control of costs by formulating a reasonable, state-operated system, using present investments to develop an orderly and smooth transition. The state, as initiator and operator of a mixed system of public and private, large and small facilities, will maintain cost control and be able to spread out start-up costs over a longer time, making a transition to a system based largely on community residential facilities smooth and effective. Our proposal responds to these issues coherently, and will result in an effective, client-centered care delivery system.

*"We are developing a gigantic care system that
is for the benefit of the care-givers."*

(A Hennepin County Social Worker)

OWNERSHIP OF RESIDENTIAL FACILITIES
FOR MENTALLY RETARDED PEOPLE IN MINNESOTA

April, 1984



All For-Profit Concerns: 55.7%

All Non-Profits: 43%

4. Age of Residents:

Services to developmentally disabled children are more expensive than services to adults. However, Hill and Lakin have shown, among the trends in residential services for mentally retarded people, "most notable was a decreasing proportion of children and an increasing proportion of severely/profoundly handicapped residents¹⁴. There is a tendency, especially given the broad range of in-home services that may fall under Medicaid coverage, and the accessibility of Day Activity and school programs, for developmentally disabled children to be in the home when possible. Historically, most retarded people enter the state service system when they reach adulthood, or when aging families can no longer care for them. It is well to remember that in the future, today's children will need to be accommodated outside of the home, but may not be able to be if a state-wide system is dismantled.

"My grandmother is 94. She's taken care of my retarded uncle all his life, but she just can't do it anymore. There is no one else in the family who could do it, either."

At the present time, there are not sufficient community residences for those people in state hospitals who could appropriately be placed in communities. Trends come and go in the ideology of what setting is seen to be most appropriate for retarded people. We can hope that the siblings of retarded people now with their birth families will care for those people when their parents no longer can, but is that a reasonable hope? Should state policy be based on that kind of hope? What will happen in 10 or 20 years when many of those families need facilities outside the home for their retarded family members? It makes no sense to begin again a cycle of constructing expensive institutions because the older institutions are gone. The best way to anticipate peaks and valleys in the population of retarded people who require out-of-home care is to develop a flexible, responsive system that can accommodate those peaks and valleys smoothly. There is little ripple effect at present: few private facilities have come into existence to meet the needs of the present hospital population. The lag-time between demand and supply is too long and the county social service system is grossly overburdened.

¹⁴ Hill, B.K., and Lakin, K.C., "Trends in Residential Services for Mentally Retarded People, 1977-1982", (Brief No. 23). Mpls. Center for Residential and Community Services, U of M, Department of Educational Psychology, 6/84.

What would be the situation if there were no hospitals to serve as intermediate residences for the population of developmentally disabled people? It is frightening to contemplate.

Minnesota can redefine the care system for developmentally disabled people to make it responsive to the needs of clients and supportive of people who care for them daily, whether in a family or other program. The state can facilitate a long-term vision of social policy that is conscious of costs and at the same time looks further than the next biennium. Only with such a vision can we seriously address the needs of retarded people and those who are committed to caring for them.

Spend some time with social workers who have clients in the state hospitals, and you will find that most of the clients have no family. They are adults who have no biological family, or whose family members are disinterested. There are few mechanisms to facilitate surrogate families, and what mechanisms there are need improvement. This lack of family networks will continue to be the case, as retarded people now with their families grow older, and no one is left to care for them. These are the circumstances that the state must anticipate.

"Of our 8 residents, only 3 have families. Two of those families are elderly. There is only one parent advocating for her child."

(A Private Group Home Counselor)

There is, in addition, another demographic trend, noted by Hill and Lakin. Birth records in Minnesota indicate that while the number of births of disabled infants is declining, the survival rate for severely disabled infants is increasing dramatically¹⁵. What this means is that over time, the proportion of developmentally disabled people with multiple, severe handicaps will increase. Costs of services will likewise increase as more staff and more highly specialized services are required, and many more children are not able to be adequately cared for in the home.

¹⁵ Minnesota Department of Health, Minnesota Center for Health Statistics. "An Overview of Birth Defects in Minnesota, 1950-1980." St. Paul, 1/84.

5. Profit/Non-Profit Status:

Non-profit residences and foster homes continue to be the least costly types of residential facilities for developmentally disabled people. This is especially significant in Minnesota, where 55.7% of residences are operated for profit, housing 59% of the retarded who are not in state hospitals. As Feder and Scanlon have found, for-profit agencies will prefer patients who: 1) pay more; and, 2) require little attention, in order to maximize profits¹⁶. In addition, the number of actual ownerships is far less than the number of residences, and there is significant evidence of inter-locking ownership throughout the state.

Of the 322 community residences in Minnesota, 179 are operated for profit. At the surface, those 179 residences are owned and operated by fewer than 66 business corporations. Among those corporations, many, especially the larger urban businesses, share board members and other significant staff members: there is horizontal interlock among the residences operated for profit. There is, in addition, vertical interlock, whereby a group of residences is operated by a business that also owns construction companies, plumbing and heating companies, consulting agencies, and other service providers that contract for services with the company owning group homes. Minnesota is in the unfortunate position of initiating and subsidizing private, for-profit businesses at several levels, both vertically and horizontally. Minnesota is, in a sense, over a barrel to profit-making providers. These for-profit providers have been created and subsidized by the state and now exercise substantial leverage on government through rate charges for the services they are mandated to provide.

SOCIAL COSTS

When the large proportion of for-profit programs for developmentally disabled people in Minnesota is considered, three issues other than cost arise:

- a) Accountability;
- b) Centralization; and,
- c) Continuity.

¹⁶ Feder and Scanlon, cited in Citizen's League Report, 4/25/84.

a) ACCOUNTABILITY:

"Longitudinal research on community-based facilities has been made even more difficult by the large and rapidly growing number of such facilities, the frequent dispersion of responsibility for various types of facilities across multiple state agencies, the lack of state-wide registries, facilities' relative lack of stability, and by the absence of uniform operational definitions.¹⁷ There is simply no way to find out what actually happens in many community facilities. Low-paid staff are fired if they make complaints or raise issues of care levels; no one else has opportunity to know what is going on. County social workers have huge caseloads and cannot adequately monitor what happens to each client on a daily basis. There is talk of decreasing caseloads for social workers, but even with the present population in the community, to reduce caseloads to a manageable level would require quadrupling the number of social workers in Ramsey County alone and tripling the number in Hennepin County. Most frightening of all, an extreme position that advocates placing every retarded person in a foster home would mean that 8,000 foster homes in the state would require monitoring.

"The director of the group home I work in used to be a counselor here. He was demoted and reprimanded. Then they made him director!"

(A Group Home Staff Member)

The potential for abuse, for warehousing and inadequate care is enormous. The entire program of care for retarded people, paid for by federal, county, and state monies, is slipping out of state monitoring of cost and quality control.

b) CENTRALIZATION:

One important motivation for moving people out of hospitals and into community settings was to decentralize a structure that was seen as too ponderous. Decentralization has not occurred. Most of the community residences for retarded people are ghettoized in Minnesota's urban areas. Most residences are owned and operated by a few companies, and there are interlocks among the companies at other levels. Decentralization into a regional system has not happened, but

¹⁷ Hill and Lakin, "Trends in Residential Services for Mentally Retarded People: 1977-1982," (Brief No. 23), CRCS, 6/84.

could happen if the present hospitals are developed as cores for regional networks of a state care system.

Decentralization has resulted in a few instances, but in many cases the residents and staff of community residences in Minnesota's smaller towns now suffer from isolation. Building a network on a regional basis will provide the coordination and interaction those isolated residences so desperately need.

Past mechanisms for deinstitutionalization have not provided for sufficient control in rural areas over where and how facilities are sited and developed. When there is talk that county budgets for social services will increase 150% to accommodate deinstitutionalization, we need to correct that imbalance. Cooperation is essential between the state and counties, and the development of a state-operated system, regionalized throughout the state, is an ideal vehicle for that cooperation.

It should also be remembered that a large part of the cost differential evidenced in non-profit residences and foster homes is due to a reliance on donated equipment and services on the part of providers. As Hill and Lakin note, foster homes "offered unusually low cost care, primarily because of high levels of donated 'staff time and capital costs, especially housing."¹⁸ It is very well to have low-cost care, but as we have seen, monitoring becomes impossible with a proliferation of foster homes, a problem which may offset the lower cost of such care. Continuity is also an issue: foster homes are the least stable type of facility. Costs are likely to rise if very disabled people, needing expensive equipment, are to be cared for in foster homes.

c) CONTINUITY:

As Hill and Lakin noted, "larger facilities tend to be more stable."¹⁹ There is ample evidence that continuity is particularly necessary to the well-being of

¹⁸ Hill and Lakin, "Classification of Residential Facilities for Mentally Retarded People," (Brief No. 24), CRCS, 1984.

¹⁹ Hill, B.K., Bruninks, R.H., Lakin, K.C., Hauber, F.A., and McGuire, S.P., "Stability of Mental Retardation Facilities for Mentally Retarded People: 1977-1982". (Brief No. 22), Minneapolis, Center for Residential and Community Services, 6/84.

developmentally disabled people²⁰. Minnesota has cause to worry about continuity given the large proportion of residences that are run for profit in the state. Recent closings of medical clinics owned by business corporations bring this worry home. When facilities can close at any minute because the profit is not sufficiently large, or because state regulation is found onerous, we must consider both the cost and effect on residents. There is also the worry that displaced residents will not be able to be accommodated in an already overburdened care system. Hill and Lakin comment: "as deinstitutionalization continues and the use of small community-based settings increases, it will be even more important to identify ways to increase the stability of these facilities."²¹ State-operated facilities, whether institutional or community based, are by their nature stable.

6. Facility Size:

Other than in foster homes, costs decrease as size of facility increases. Cost factors not now accounted for must be considered when any comparisons are made. For example, in Semi-Independent Living Situations (SILS), "per day reimbursement [was] difficult to reliably assess ... because residents often receive subsidized rent or were subsidized directly and paid their own living expenses"²². Again, type of facility, whether Class A or Class B, and the practice of "skimming" must be taken into account. The days of warehousing in state hospitals, and accompanying inhumane conditions are passing. What is still present, however, is a large state investment in buildings and land, a broad capability to serve many levels of disability, a highly trained and large staff, all of which will be economic losses to the state if the entire hospital system is dismantled. There are many ways that the present system can be utilized to take advantage of this investment, to develop a broad range of services to Minnesota's developmentally disabled people, and to provide the best care possible while maintaining cost effectiveness.

²⁰Carsrud, Carsrud, Henderson, Alisch, and Fowler, "Effects of social and environmental change on institutionalized mentally retarded persons: the relocation syndrome reconsidered." American Journal of Mental Deficiency, 84, 1979.

Rober, D., and Berkson, G., "Social ecology of supervised communal facilities for mentally disabled adults: III Predictors of Social Choice." American Journal of Mental Deficiency, 85, 1980.

²¹Lakin, Bruninks, Doth, Hill, and Hauber, "Source Book on Long-Term Care for Developmentally Disabled People." CRCS, U of M, Report No. 17, 1982.

²²Hill and Lakin, "Classification of Residential Facilities for Mentally Retarded People," (Brief No. 24) CRCS, 1984.

7. Family Owned and Operated Facilities:

Family owned and operated facilities are most often small, located outside the urban areas of Minnesota, and rely to a great extent on donated staff time and capital costs. Frequently, family owned facilities are outgrowths of foster homes and are operated by parents of retarded people. They are certainly cost effective, but questions of continuity and accountability remain. What will happen when the families that now operate residential facilities age, and can no longer maintain the facilities? Where will the residents go? This proposal responds to the need for a continuing long-term vision to address the needs of developmentally disabled people.

8. Licensed Capacity:

Costs of residential facilities, while lowest for foster homes, show a decrease with increasing size of resident population. This is especially significant when we remember that most of the smaller facilities are operated for profit, and most of the facilities that care for severely disabled people tend to be larger. Costs in smaller facilities, already proportionally higher, are bound to increase if all the retarded people in Minnesota are to be cared for in facilities housing no more than six people.

LEVEL OF CARE

The level of care required by developmentally disabled people is directly reflected in costs, including costs for special equipment, construction, and staffing. But there are other concerns as well; there will always be tension between the need of the state to be frugal and the wish to provide the best care possible for our retarded citizens. In 1983, the Minnesota Legislature authorized DHS to make changes in Rule 52 in a strong effort to control the costs of Intermediate Care Facilities for developmentally disabled people. What is needed now is a mechanism for capping the profits of for-profit care providers, and redistributing revenues so that programs for retarded people in Minnesota are as effective as they can be.

STAFF: TRAINING AND TURNOVER

Estimates from other states (Rhode Island in particular) indicate that hiring state employees in Intermediate Care Facilities may add as much as 15% to the staff cost of care for developmentally disabled people. Our research indicates that this would be money well spent. The loss of training and experience of staff is an invisible economic loss to the state economy, should the hospital system be closed down with no provision made for using that skill and training. If, as in Michigan, Minnesota instituted a profit ceiling for vendors, or other mechanisms to redistribute dollars away from administration and profit and toward care, there would be little or no added difference in state-operated community homes that used state employees.

With no clearly articulated state-wide plan, costs will increase in any case as private for-profit agencies encounter populations of clients they have heretofore not served. Private vendors, hiring people with little or no training or experience, and paying the lowest possible wages, have no incentive to encourage in-service training beyond the minimum necessary for profitable operation. Staff in private group homes are taught how to give medication so that they can be certified to do so, but for many that is as much training as they will see. (The researcher of this report applied to several group homes that were hiring staff. Not once was any training discussed in interviews. The only conditions of employment were a Mantoux test and certification to dispense medication.)

"Our training? We had breakfast on Monday with the houseparents who were leaving. We started Wednesday morning!"

(A former houseparent in a group home)

In contrast, state hospital staff are provided with a broad range of training and are encouraged to participate in training. Reorganized state hospitals, operated as regional centers in a state-wide system of care for retarded people, are ideally suited to continue as training centers for a network of group homes. Coordination with area Vocational Technical Institutes, Community Colleges, private educational institutions, and State Universities is already in place in some areas, and can be broadened as the pool of prospective students increases.

Consistency of training programs across the state will benefit both the state as a whole and the retarded population. The state will have quality of care assurance and a state-wide standard now desperately needed. Retarded people will have the consistency of care and treatment required for their well-being; those requirements have been documented in study after study²³. Adequate staff is the most important factor in providing care to developmentally disabled people and adequate staff can only be provided when salaries are sufficient and staff can be assured of stability and progress in their employment. At present, neither is guaranteed outside the hospital system.

Staff turnover has a direct impact on consistency of care. Social workers and private group home staff report again and again that turnover rates are very high in private, for-profit facilities.

"Last year, 8 of the 12 staff left."

(A staff member, private group home)

"No one who worked here when I started 6 months ago is still on staff, except the owner."

(A staff member, private group home)

It should be noted that one study indicates that staff turnover in Minnesota's private group homes is remarkably low²⁴. But there are several problems with the study:

- 1) Results were based on mailed-in responses rather than site visits;
- 2) Owners of group homes responded to the questionnaire, not line staff;
- 3) Owners were asked to explain turnover rates; and,
- 4) Nowhere is the discrepancy accounted for between owner reports and the reports of social workers and staff.

Staff also report that, even when they might like to continue the work, they could only work in group homes as "interim" work-while finishing a degree, looking

²³ cf. note 18.

²⁴ Metropolitan Council of the Twin Cities Area. "Personnel Turnover in Community Group Homes for Mentally Retarded People", March, 1983.

for a better job, and so on. Low wages and poor benefits packages also contribute to these problems. Think for a moment about working as a relief houseparent, from 5 p.m. Friday to 10 p.m. Sunday, 53 straight hours, with 8 people to care for, at \$3.00 an hour. Could you hold another job during the week {or would you be too exhausted)? Consistency of care is illusory in cases like this, when one set of staff leaves and there is no continuum of care.

There are group homes that encourage in-service training, that pay more than minimum wage. But there is at present no way to ensure either. There are also people who will work for low wages and no benefits for years, but they are very few, and certainly this phenomenon should not be relied on if the state is to develop an adequate system of small residences.

An active training program, organized at the state level, operated out of regional centers, and using state staff, can be a valuable asset in a mixed system of public and private group homes. Such a resource, available to all group home staff in the state, will encourage consistency and communication throughout the care system, and will be geographically accessible. Access to training and contact with staff of other group homes will also go a long way in preventing the abuse of staff and residents that is possible in isolated small residences, making monitoring simpler.

Most residences have, on paper, a staff development program. Common sense and comparable experience in other fields suggest that what is on paper is not a guarantee that training is available. What, realistically, is the likelihood that staff, paid minimum wage, already overworked, will invest their own time and money in further training? What we desperately need in Minnesota is a consistent plan, and consistent implementation of that plan. Staff enrichment and stability are crucial. In the long run, shifting revenues away from profits and into staff development can only benefit the state and its retarded citizens.

It is simply not possible or advisable to hire people off the street, at minimum wage, to care for profoundly retarded people with other physical and behavioral disabilities. The expertise to care for such people is present in the state hospitals now in people drawn to and committed to this critically important field.

A carefully planned state-operated system of group homes would make the best use of staff, coordinating movement of staff and residents away from hospitals and into smaller settings. It is particularly important to bear this in mind as the nature of the disabilities of the people moving out of the hospitals changes, and as the field develops across the continuum of care.

In addition to consistency of care and training, such a system could also provide the flexibility now absent. It is not to the benefit of clients, nor cost effective, when:

- 1) residents are permanent but staff and programs change frequently;
- 2) clients are lost by the monitoring system;
- 3) clients cannot be readmitted to a given program without a long wait and additional legal proceedings; and
- 4) there is no planning for respite care.

We have touched on staff and program stability. The situation at present is this: clients are removed from state hospitals because there is a bed in a group home [in the financially responsible county] not necessarily because that particular client is ready for a group home. Clients who should be in group homes wait in hospitals because there is none in their hometown. Files go to the group home with the client, and some monitoring by the hospital is possible for a maximum of 60 days. We hope the group home staff have time to read files, since that is all they will know about a given client's history. After 60 days, the resident is essentially lost to the hospital staff, and is monitored by a local county social worker unfamiliar with that client at long intervals. If, during the 60-day period, the resident is having problems, readmittance to the hospital is possible, but placement in yet another group home is more likely, since the hospital is under orders to reduce its population. If problems arise after the 60-day period, the resident is shunted to another group home and/or admittance procedures are begun for the state hospital.

In an improved situation, any client moved out of a hospital would be familiar with staff and other residents of the group home; hospital staff could be transferred to the group home if they wished, when residents were transferred. This

would increase continuity, easing the transition for the resident, and provide vital linkage among staff. But such a process can work only if there is parity of wages, benefits, and job security between the staff member's employment in the hospital and employment in the community setting.

The criterion for placement in such a system would be the best interest of the resident, not just the availability of a bed. Maintaining some persons in the hospital population, when that is appropriate, and developing group homes where resident, staff, and geographical location coalesce, is a reasonable and clear alternative to the present situation.

RESPIRE CARE

When state and federal policy encourages families to keep developmentally disabled people at home, provisions for respite care are sorely needed. Imagine having 24-hour, 365-day care for anyone, and the need becomes clear. If we believe families are the best place for retarded people to live, and cost effective for the state, we must provide the possibility for short term relief from that demanding care, or the care system will be flooded by retarded people whose families simply "burn out", unable to cope. Respite care should be an essential part of the program in hospitals and group homes run by the state. If regional centers provide screening, evaluation, and program development for retarded people throughout the state, wherever they reside, respite care would be a natural adjunct to that regional network. Familiarity of staff, client, and family with one another would mean that respite care would not be simply a traumatic dumping of a client, but an easy transition.

ACCOUNTABILITY

A frequently overlooked advantage of the present public system is that staff functions "in a fishbowl", as one staff member put it. Clients are monitored, but so are staff, and potential abuses can be quickly and efficiently dealt with. Identifying and correcting abuses is more difficult when a group home is isolated and private, or quietly centralized within a private business chain. In one group home, when staff brought complaints about conditions for residents, the director said, "you don't like something? Quit. There are plenty of people I can hire

who won't complain." In such a situation, the potential for abuse is enormous, and there is no guarantee of effective internal procedures by which abuses could be corrected. There is little or no public access to private group homes, and staff are frequently at risk if they raise complaints.

Accountability and monitoring are already problems for the social service system. Huge caseloads, an increase in administrative and planning duties, and corresponding decreases in direct contact with clients, mean that county social workers are forced to rely on reports by providers or minimal contact with clients. There are vague promises that caseloads will decrease, but that can only mean that counties will hire more social workers. Will that really happen? In sufficient numbers? If a caseload of 25 clients is estimated to be most suitable, and a social worker has a caseload at present of 60-120 people, is it realistic to suppose that quadrupled staff will be added to make up the difference? If we then imagine the 1200 residences proposed, monitoring and accountability are out of the question.

The large proportion of private, for-profit providers raises an additional issue. There is surely a conflict between state standards and regulations and the natural tendency of businesses to maximize profits and resist or outwit regulators. It is recognition of this issue that makes state standards necessary.

"I visited a friend in a large private facility for non-ambulatory residents. One room not visible from the staff desk had been blocked off with a chair and large rolling dividers, so that the minimal staff could 'keep an eye on' all of the wheel-chair-bound residents. Unfortunately, through that room was the main fire exit. Of course I can complain, but then they (the staff) see me as a trouble maker and stop being cooperative. And I can't be here all the time."

(Researcher)

A care system that must rely increasingly on self-monitoring of group homes cannot provide quick and effective redress. The advantage of state-operated and staffed group homes, developed in a coherent network, is that mechanisms are already in place for such monitoring. Such mechanisms can be improved and strengthened under this proposal.

One consortium of group home owners argues that the state would be an inappropriate owner/operator of group homes because of "conflict of interest". The claim is that the state is in a conflict when it both runs and monitors a program. The charge of "conflict of interest" is easy to make, but what can this really mean? The state is not making a profit, and has no reason to circumvent its own regulations to increase that non-existent profit. The state does have an interest in a consistent, cost-effective program of quality care. Employees have an interest in job security and in doing what is best for a client, not in maximizing profits. Supervisors have an interest in running a good and a smooth program; they are not owners. The wages of supervisors are not contingent on keeping beds occupied when they work for the state. What is the conflict? In reality, funding comes from several sources, federal, state, and local, and would continue to do so in a state-owned and operated system; monitoring that system falls largely to DHS and the counties. Procedures are already in place in hospitals to correct mismanagement by supervisors, potential abuse of clients, and grievances to staff.

The push toward decentralization of the care system for retarded people in Minnesota has resulted in the placement of many smaller group homes in isolated towns throughout Minnesota. When staffing, equipment, and services are minimized so to increase profit, nothing but life support is provided to residents.

"His home-like, attractive living unit has 16 people... There is around-the-clock coverage with dedicated, caring staff members. His houseparent is a young man who is one of our family's best friends. If Medicaid money is taken away from people in institutions having more than 15 beds, it would pull the rug right out from under our son."

(Parent of a Hospital Resident)

"As with all human beings, there is no "Oneness" to the retarded population, but a complicated array of malfunction within an already complicated structure of human existence. Hence, there can be no one answer to the problem of adequate care for the retarded. What must be established is a system of care that is capable of matching the myriad of needs, present in the retarded population."

(A Parent)

When the board of a private, for-profit group home consists of the grocer, doctor, and contractor who provide services to the group home, that may provide a link with the rest of the townspeople and increase normalization in the lives of retarded people. But it can also lead to critical conflicts of interest, outside the fiscal control of the state. The important networking and board-to-town linkage could be maintained, and potential conflicts avoided, if the state developed group homes which encouraged local participation, while maintaining the ability to monitor costs and quality of care.

The state must meet the requirements of litigation and legislation - Federal standards and policies and court-decreed standards and policies. Other than building codes, the primarily federal policy affecting care delivery systems is the Medicaid waiver. Originally promoted as a means of diverting funds away from large institutions and into community-based care, the waiver system has been seen as a panacea for any and all problems in institutional care delivery systems. There are some families who are able to keep retarded children in the home because of the financial assistance offered by the waiver system. The overall effect, however, has been to undermine the hospital system without providing alternative care delivery. The Medicaid waiver allows reimbursement for some services only if the client is in a residence for 15 or fewer people. The services covered are only some of the services that would normally be available in a hospital setting.

Anticipating results of the waiver, caseloads for social workers have increased at the same time that many more administrative duties have been added to their work. There are promises that caseloads will decrease as more social workers are hired, but this is not happening. Counties must initiate such staffing changes, and few counties are willing to triple or quadruple their social service staffs. The waiver has become, not a cure-all, but only a placebo.

WHAT IS THE RELEVANT LEGAL BACKGROUND:

U.S. District Court, District of Minnesota, No. 4-72-Civ. 451: 1974 - Welsch vs. Likens (aka W. Noot, W. Levine, etc.) U.S. District Court affirmed that mentally retarded persons have the constitutional right to treatment in the least restrictive alternative.

1975 - New York State ARC vs. Cavey: Court required the state to:

- 1) Provide least restrictive living conditions possible;
- 2) Reduce population at a state institution;
- 3) Develop community placements.

1977 - Pennsylvania ARC vs. Pennsylvania: Segregation of mentally retarded persons was a violation of the 14th Amendment right to equal protection.

1979 - Michigan ARC vs. Plymouth Center: The state must develop community residential alternatives to reduce the population in a state institution.

1978 - 81 - Several zoning decisions in Michigan in which group homes were found to be "substitute families" and should be so treated.

1984 - U.S. Court of Appeals ruled that there is no right to a least restrictive environment for dependent adults. The standard is "adequate professional judgement", not a constitutional issue.

The fact there there is no state-wide integrated plan for how Minnesota will address the needs of retarded people is reflected in responses to litigation and legislation. The Medicaid Waiver requires that beneficiaries live in groups no larger than 15; the Welsch vs. Levine consent decree calls for a "least restrictive alternative" to institutional settings, focusing on "family size" groups of six. Neither calls for the abolition of the public state hospitals; neither specifically insists that all retarded people are most appropriately placed in group homes, yet that is how both have been interpreted until now. There has been widespread opposition to proposed federal legislation, the "family living amendment" requiring that all retarded people must live in small settings in order to receive subsidies. Widely perceived as totally destructive of state hospitals, these changes would limit available placements for people who may be most appropriately placed in larger settings, including hospitals.

"Institutions have a critical role to play in the continuum of services. They can cope with the care and training of very difficult cases that community facilities are not well prepared to handle. One benefit of institutions is that they can marshal a critical mass of professional staff for specialized services."

(Parent of a Hospital Resident)

NATURE OF THE CARE SYSTEM

State institutions for developmentally disabled people came into being for several reasons, among them:

- 1) Families were unable to care for their retarded family members;
- 2) Retarded people needed protection from a society that was frequently hostile and didn't understand them. Abuse of retarded people in the home and community was rampant;
- 3) Some retarded people were dangerous to themselves and needed restraint. Some were dangerous to others, and society needed protection from them.

Although there may be more understanding in the community today, these facts still need to be taken into account. Severely disabled or medically fragile people, who require 24-hour care, are a huge drain on family finances and energy, and may not be able to receive the care they need in a home setting. While it might be admirable when families try to provide such care, it frequently results in severe strains on family life.

Nor can we return to the days of retarded people being locked in closets or kept in a bedroom, to being taunted on the streets or kept in virtual slavery. And whatever the virtues of community life in family-sized households, we must seriously address another terribly difficult question. Is it fair and reasonable to expect families in small towns or residential neighborhoods to welcome a group home for residents from a locked ward, who are potentially dangerous? Is it fair to remove those residents from a campus setting to a residential neighborhood where they will be even more restricted, met with hostility, and never be a part of the community? Is it fair to force someone into a group home who must be drugged just to be there, when that same person could do without drugs in

a hospital setting? What does "normalization" mean in such contexts? These are tough questions, questions that must be addressed if state policy is to be coherent.

"Community acceptance is a real problem. Some clients do well. But do people really want a house next door full of people from a locked ward? They don't have to be Neanderthals to want to keep violent people out of their neighborhoods."

(A Hennepin County Social Worker)

There is a television public service announcement running these days, very well done, asking viewers where they get their information about retarded people. 25 Pictures of a smiling, apple-cheeked boy are shown, while a deep voice in the background says, "some people say Mikey can't enjoy, learn, participate, communicate..." The point is that Mikey, though retarded, is a delightful child, a child you would enjoy knowing.

But all the Mikeys are in the community. People now in the state hospitals are "hard cases", with many disabilities and behavior problems, people rejected by private group homes. In many instances, forced normalization can be damaging to them and far from normal. To spend half the day in a wheelchair-accessible van is not normal, especially when the alternative is a residence and Day Activity Center on a campus. Is it normal to go for hamburgers in groups of 12, piling in and out of that van, being handed money at the register, especially when everything you do is with those same 12 people? Approximating normal family life as much as possible is unarguably a good thing. But as "normalization" has developed, group home residents invariably function as a unit, and there is little or no individualized attention for residents. This is due in part to staffing levels, to needs of providers to keep staffing expenses as low as possible.

Bizarre, aggressive, or potentially dangerous behavior is amenable to change with proper staff. With adequate resources and trained, committed staff, many people can do well in community settings. But it is essential that we not dump people, that adequate, well-staffed facilities be in place in the community before

Association of Residences for the Retarded in Minnesota, 1984.

residents are demitted from hospital programs. The transition is crucial to effective normalization, and developmentally disabled people must be the primary concern.

"How many clients are given lots of meds in order to be in the community? Hospitals do a 'drug holiday' to establish a baseline and minimal medication. How many people in the community are just tranquilized into 'normalcy'?"

(A Hennepin County Social Worker)

The problem in Minnesota right now is that there is no system. Closing down the present public system was not the intent of the Consent Decree or of other litigation. Improving conditions for developmentally disabled people was the intent. Closing the hospitals is not enough to ensure that retarded people live in a normal community context. In some instances, private, for-profit group homes have up to 170 residents, non-profit group homes up to 108 residents. "Deinstitutionalization" has meant attacking the state hospitals, highly visible targets, but there is no mechanism to close down large, for-profit homes in the community. It is hard to see how a hospital such as Faribault, where residents are in small living groups, is any more an institution than is a private residence for 170 retarded people. Present fiscal controls do not provide for the phasing out of large private residences—why then focus only on state hospitals?

Two difficulties have arisen in the response of the private sector to the need for Intermediate Care Facilities. The response has been inadequate in that not enough placement for difficult clients have been developed by the private sector. What placements there are have been in facilities that accept the least disabled clientele, resulting in de facto segregation of people with severe disabilities or behavior problems. Day Activity programs have also been lacking; in some counties there is a 1 1/2 - 2 year waiting list for all day programs.

At the same time, Intermediate Care Facilities for Mentally Retarded People (ICF-MR) are largely concentrated in urban areas. This means that the original intent of the deinstitutionalization movement has been subverted. Retarded people who are moved out of state hospitals are not necessarily in "home-like" environments, and they are concentrated geographically.

"The local community is highly critical. What the residents can do is very restricted. Everyone has to be on their best behavior and dressed in their Sunday best, just to go get ice cream."

(Group Home Counselor)

In closing the state hospitals, the state will create unemployment pools in the communities where the hospitals are located. Simultaneously, the power of the state to effect economic development outside the metropolitan areas is nullified by the concentration of group homes. The state could and should be using its economic power more wisely, by spreading jobs and facilities around the state. A coordinated state-wide system of care for mentally retarded people can help accomplish this goal.

THE FUTURE

Rhode Island and Michigan have attempted state-initiated deinstitutionalization of mentally retarded people with varying results. There is much we can learn, much we can avoid from these two programs.

Michigan has begun moving from a large state hospital system to smaller intermediate care facilities. The state leases homes and contracts for administrative services. Rent on the homes is determined by an independent appraiser, and a 12% profit ceiling is maintained. The landlord is responsible for construction, maintenance, and major repairs. The administrator/licensee supervises services, staff, and budget, and must have appropriate background and training. Residents are housed according to six levels of disability, and per diem rates are established by disability level. Funding comes from several sources, including the Michigan Department of Social Services, Department of Mental Health, Social Security Administration, and Title XX Medicaid. The result is segregation by disability level, and funding increases as ability level of clients decreases.

Some effort was made in Michigan to offset staff disruption. Unfortunately, this effort was disorganized, with no clearly articulated state-wide goals, no clear lines of authority, and ineffective communication²⁶. Staff turnover was a

²⁶ Mowbray, C.T., Tableman, B., and Gould, R., "Reduction in Force: A Summary, and Analysis of One State Agency's Experience." New England Journal of Human Services, 1984.

problem. Some transfers to other state departments occurred. Normal attrition did not, however, account for the disappearance of large numbers of staff from the state system who did not seek employment in group homes.

Michigan does, however, require 120 hours of training prior to or early in employment, training that includes information on developmental disabilities, emergency procedures, health maintenance, and community resources.

In Rhode Island, a much clearer attempt has been made to accommodate staff needs²⁷. The state solicited preferences from staff about relocation and the conditions for relocation to group homes, working closely with AFSCME. A formal agreement was reached that normal attrition and transfers to groups homes would accommodate all staff. Staff would maintain collective bargaining rights and be provided with retraining where needed, as they moved into group homes and other community settings.

Transition was smoothed by intensive training of staff and an interim stay for both staff and residents in a small building on the campus of the state hospital. This transition period was followed by a move to a house in another town. Staff and clients were often transferred together, with a reduction of one-third of the hospital population over three years. Savings in the state hospital budget have been transferred to a variety of community programs.

Rhode Island, by working closely with AFSCME, succeeded in developing a smooth and effective transition from a large institution to a number of smaller residences and a far smaller hospital population.

Minnesota has an opportunity to learn from and further develop a coherent plan for a comprehensive public system of care for developmentally disabled people. There are two important parts of such a plan:

1) What will the future system be? 2}

How do we get there?

²⁷ Shafer, Elizabeth, "The Movement of State Workers from Institutional to Community-Services for Mentally Retarded Individuals: a case study of Rhode Island's Labor Management Agreement," May, 1982.

A system of care for developmentally disabled people must include a range of services. Present state hospitals, reorganized as hubs of regional networks, can provide:

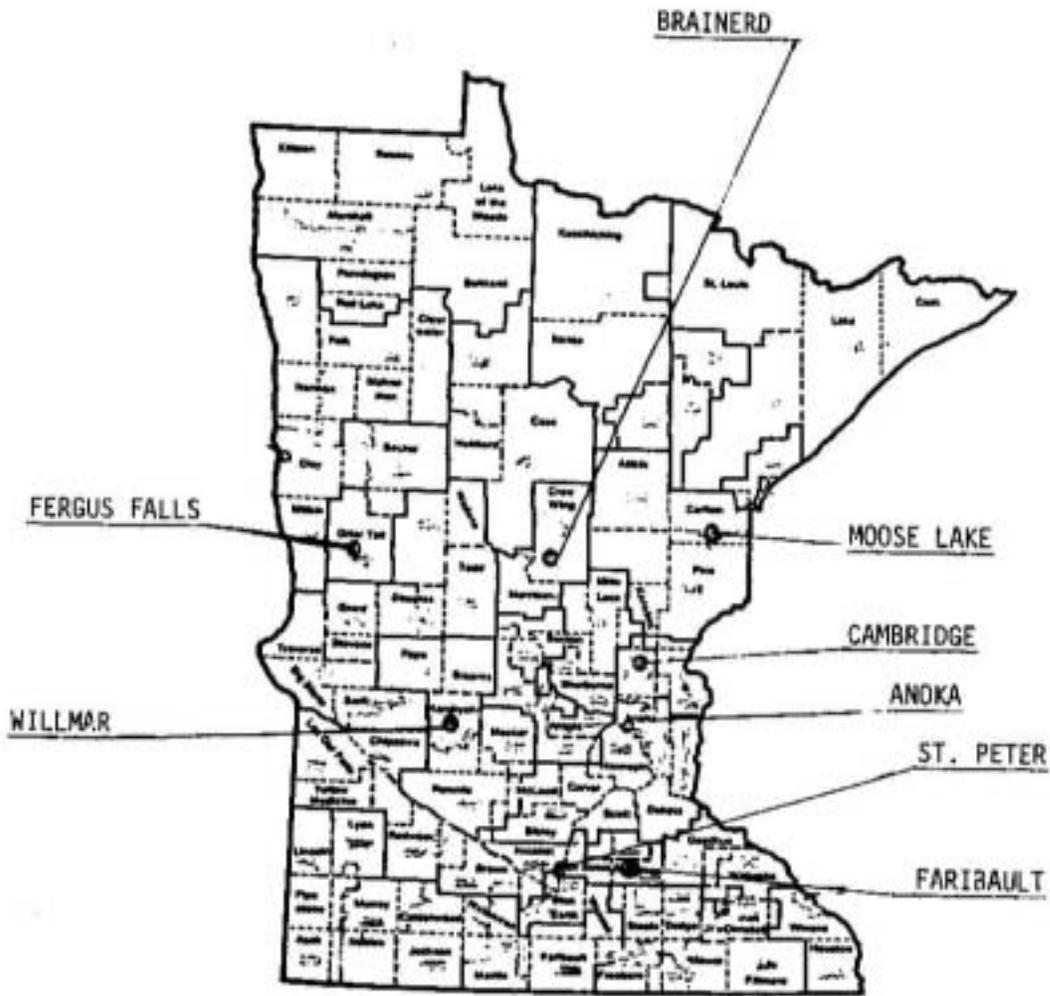
- 1) Long-term care for some residents;
- 2) Respite care region-wide, including emergency care;
- 3) Screening, evaluation, and program development for clients, families, and group homes;
- 4) Coordination of placement for residents;
- 5) Centralized expertise available to the entire region;
- 6) Monitoring and quality control for the system overall;
- 7) Specialized equipment and facilities; and,
- 8) Training for staff in the region, coordinated with local educational facilities.

Regional networks will consist of the reorganized hospitals as hubs, a full range of residences for all categories of clients (ideally in groups no larger than 15), group homes (SLA, SILS, ICF-MR both public and private), Day Activity Centers, and other programs.

The state, through construction or lease, will establish community residences with future residents in mind. Location and level of care are known factors, while additional groups homes can be added as the population to be served is identified, in the community and the state hospitals. Present state hospital day programs would be redesigned to serve the region, especially in rural areas.

Regional Centers for the Developmentally Disabled will have manageable goals and populations to be served. Small residences will have access to information, services, equipment, and training. Staff will be able to maintain consistency and stability, and have access to expertise and education. As state-operated community facilities are developed, local citizen participation can be earnestly sought; staff are integral to this process. The result will be true community life for as many of Minnesota's developmentally disabled people as can benefit.

LOCATION OF PRESENT STATE HOSPITALS



(Geographical distribution calls for one more care hub
in the northwestern or north-central region.)

Careful consultations between the State and AFSCME over staffing will mean that the staff transitions to regional networks can be smooth. Residents of present programs will have continuity, staff will not be in limbo, and valuable assets will be maintained for Minnesota. Staff can be given experience in non-institutional settings prior to client placement in a public community facility. Hospital staff can meet with private group home staff for enrichment training relating to client needs. Communication and interaction throughout the system will promote consistency and reduce isolation.

Day Activity Programs can be offered regionally as needed. Because of their training and experience, state employees working in Day Programs could also develop new approaches, such as supportive work models for clients. As deinstitutionalization progresses, state employees will be well situated to enter this new growth industry, the development of day programs, in the hospital regions.

Gradual scaling down of institutional services will allow for normal attrition of staff. Retraining will enhance the transfer of state employees from large institutions and into community settings. Programs for mentally ill and chemically dependent people can be upgraded by staff transfers. Providing time to fill employment gaps created by deinstitutionalization will foster economic development in hospital towns and regions, rather than create pockets of unemployment, reduced real estate values, and other unfortunate economic results of hasty dismantling.

What Minnesota needs is a care system for retarded people that is uniform and coherent, a system which will include smaller facilities where that is of benefit to residents. At the same time, such a system must not waste present state investments in staff and buildings. This is particularly true when those investments can be used wisely to provide a cost effective and reasonable care delivery system.

AFSCME PROPOSAL

AFSCME proposes that Minnesota institute a project for state-owned and operated group homes and other community facilities. This project will begin in 1985 and be evaluated after two years. Recommendations will be made at that time on further expansion of the system. This project will have eight parts:

- 1) Residents;
- 2) Staff;
- 3) Interim/Training;
- 4) Community residence;
- 5) Close liaison with hospitals, including day programs and other resources;
- 6) Close liaison with community;
- 7) Monitoring (tracking); and,
- 8) Evaluation procedures (quality judgments).

1) Residents of state hospitals who are slated for placement in the community will be chosen for the Project. Clients could also come from the population of those to be diverted from placement in state hospitals, and those to be placed under the Welsch consent decree and the Medicaid Waiver. Residents will be screened and evaluated for program needs and the level of care they require. The families of residents will be consulted when that is possible, and efforts made to see that community facilities will be conveniently located. It is imperative that "adequate professional judgment" be the determining factor in any placements decided upon. Only residents for whom a community placement is beneficial should receive community placement.

2) Staff in the hospital will have the project explained to them, and positions in the project will be posted for bid, following union contractual procedures. Staff must be aware that interim residence and training are part of the project, and that relocation may be required. Staff will maintain all collective bargaining rights. Some modifications of the contract and work rules to address working conditions in the community would be anticipated and negotiated through normal collective bargaining procedures.

3) Successful bidders for positions, and targeted residents, will have a transition/training process, to get to know each other prior to a move, and to develop the skills needed for residential life in a smaller setting. For staff, this could include half-time hands-on training, and half-time working, as in Rhode Island. This interim period should be at least six weeks long. The State University System could serve as primary organizer for staff training using experts and advocates from the public and private sector to teach employees these skills.

4) Community residences will be built or leased by the state following Class B certification standards. Any adaptation of the residences will be completed during the interim period based on the needs of residents to be transferred. Such modifications as are needed may use the state bidding system and/or service, maintenance, and technical staff from the hospitals. It is anticipated that bonding will be required for purchase or building of new residential facilities.

5) Wherever possible, hospital facilities such as day programs and specialized services and equipment will be coordinated so that the project community facilities do not duplicate hospital facilities. Weekly meetings of hospital and community staff would be held through the duration of the project.

6) Community Involvement Boards will be established consisting of local residents to explain and publicize the project, and ensure that community life is a reality for both residents and staff. Staff training would include skill development in community outreach and organizing to help integrate the home and its residents into the community. Community integration is crucial. Not every private sector program has failed to develop community linkages, but few have done so to the extent necessary. Business leaders, churches, volunteer groups, and other local organizations and individuals would be actively solicited. A monthly Board meeting, incorporated with the staff meeting, would maintain these local contacts.

7) Monitoring must be an integral part of the pilot project, so that any problems or successful aspects of the project can be avoided or duplicated in the future. This should include weekly meetings among community staff and hospital staff, monthly meetings with the local board, and careful documentation of the progress of residents. We do not know, for example, if residents really are benefited simply by a smaller setting. Data from Rhode Island indicate that staff prefer smaller settings. We need to know how much time residents spent being transported and how normal the lives of residents really are. We also need to know what stresses residents find in smaller settings, particularly when residents are severely disabled. What is the effect on clients of living in close proximity to a randomly selected family? We need to know medication levels, both in and out of hospitals. We also need to know what construction and facility adjustments really work, for both residents and staff.

8) Evaluation procedures must be in place early on. Costs are obviously crucial to evaluate, but evaluations must also be made of programmatic and developmental aspects of the project. Every six months the meeting of staff and local board will be an evaluation session. At one and two year intervals, more extensive evaluations can be carried out, resulting in recommendations concerning enhancement of the system.

Such a project will be of great benefit in developing state policies regarding developmentally disabled people. We will have hard data rather than ideology.

The following key questions will have to be addressed for the future.

1) What services will the state provide? A dispersal of state-operated community facilities in multi-county areas will provide or augment the range or program options for the disabled. A range of residential and day programs would be provided, and services would be diverse to best address client need,

2) How would client interest be served? A policy vacuum exists in Minnesota with respect to the optimum use of the state hospital resources. Clients suffer as a result because program options have not developed and have not been geographically uniform, even if available. By developing state-run options off of the existing hospital base, a more uniform, locally and regionally responsive network of services will be provided to enhance progress of clients who can take advantage of options. Deinstitutionalization will be promoted and the existing log jam of unresponsive program development will be addressed.

3) How would a state-run system fit Minnesota's county based social service system? Counties have consistently supported the state hospitals, their resources and staff. The service and support capabilities of the hospitals to regions are recognized facts. County authorities state a need for more and varied community based services for hard to serve clients. Given the disability profiles of state hospital residents, counties can be expected to respond favorably to proposals that keep the state "in the business". Counties would retain their basic authority in terms of financial responsibility, but would benefit by the increased residential and day program options offered by the state.

Counties are puzzling through the confusion of Title 19 Waiver requirements that have been placed on them. Counties have been asked to perform tasks heretofore not expected of them. County social workers are being over-burdened with administrative work. Counties are estimating break the bank costs of certain waived services and increased local tax burdens to meet state expectations.

State initiative in the area of new, state-operated services, would not eliminate county initiatives under the waiver. Rather, by offering options not now present, counties would have increased flexibility to plan and change services for clients.

4) What about the economy of the hospital communities? The recently completed town meetings carried out by the State Planning Agency confirm the strong link of the hospitals to local areas. While recognizing that change will also affect economic circumstances, this proposal would significantly buffer negative economic consequences.

To take best advantage of a proposal for state-operated community based services, an evolutionary and incremental approach must be taken. In this sense, the economic health of one region or community must be seen as tied to that of the rest of the state hospital communities. In other words, a system-wide approach must be undertaken.

It is recommended that the Inter-Agency Board created by the Legislature in 1984 to oversee the State Planning Agency study be retained. This body, comprised of state agency and department heads, could effectively address the broad coordination and resource issues involved in two, five, and ten year planning for alternative uses of facilities, new industries, and job training.

5) What about existing state hospital MI and CD programs? Services to other client groups must also be addressed within a continuum of care. In the short term, as the state transfers hospital beds to community facilities for the mentally retarded, the upgrading of MI staffing in the hospitals can buffer staff disruptions while providing much-needed improvements in care inside the hospitals. Longer term, structural changes in state MI and CD programs could also fit local and regional service models. For example, state-operated, community based programs serving the hearing impaired mentally ill, or programs for pregnant women who are mentally

ill-programs not now available--could be developed using the hospital hubs.

6) How would the state-operated community based program be managed? In order to maximize local and regional responsiveness within a state-wide system, a two-tiered management approach would be necessary.

Overall coordination of state initiatives could be placed in an office within the Commissioner of Human Service's office, providing more immediate attention to the decentralized projects developed out of the hospitals. Each participating hospital would likewise have an organizational component comprised of a supportive work unit that would develop and provide professional and technical client services to the region, and a development services unit that would be responsible for creating the new community based services in the region.

This model would build regional programs off of the state hospital in a slow, decentralized manner.

7) How big an effort should the state undertake? The pace of quality community placement for a significant portion of the present state hospital population can be anticipated under this proposal. A project to transfer between 300 and 500 residents to state-operated services would best address the needs of all groups with interests in the future of quality services to the developmentally disabled.

CONCLUSION

In Minnesota, just as in the rest of the nation, the care of developmentally disabled people is changing rapidly. Support for deinstitutionalization and the normalization of retarded people exists in the courts, legislature, and advocacy groups. Policies and funding patterns at the federal level are also changing. One result of these changes has been a confusion of fiscal and quality control of services at the state level.

At the same time, deinstitutionalization threatens to destroy state assets, both physical and human, if the state hospitals are simply closed with no coherent plan for how Minnesota can re-shape its use of those assets. Structural unemployment will be created throughout the state with enormous impact on the towns where hospitals are located, if the present care-delivery system is simply dismantled.

Minnesota has an opportunity to address these issues creatively. We can foster economic development throughout the state while maintaining fiscal and quality control. We can maintain and develop assets in bricks and mortar, and assets in people who are well-trained and committed to working in a care system for developmentally disabled people. All of these goals can be met by developing a state-operated, regional system of circles of care for developmentally disabled people in Minnesota, consisting of private, county, and state services.

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