

A Position Paper
about
MENTALLY RETARDED PEOPLE
Who Are
RESIDENTS OF STATE
HOSPITALS
and
COMMUNITY BASED
INTERMEDIATE CARE FACILITIES
(ICF/MRs)



By
JOHN L. HOLAHAN
Father of Peter J. Holahan (*Age 42*)
Resident of The Faribault State Hospital
Since 1950

February 1, 1985

CREDENTIALS

The Holahan family studies and concerns about Mental Retardation began with Peter's birth in 1942.

In 1948, my wife attended the first meetings of The Association of Parents and Friends of Retarded Children, out of which evolved ARC Hennepin County, ARC US, and ARC MN.

My wife dragged me to my first meeting wherein Association President Rueben Lindh announced that he had an assignment. Miriam Karlins, who was in charge of volunteers for the Department of Welfare, had asked the Association to provide furniture for a cottage at the Hastings State Hospital. The cottage would provide respite care for retarded children from homes in which an emergency had arisen.

The following Saturday morning found me in Downtown Minneapolis begging for furniture. I got the furniture and began a career in community services which has lasted until now; Miriam Karlins has also remained active. Like Sarah Bernhardt, Miriam has retired many times. Today, she is a consultant for the Minnesota State Planning Agency, handling the nine town meetings which were held to obtain input from citizens about State Hospitals.

In 1984 I severed all my connections with the ARC's because they have become Top Down organizations and are working, with single issue intensity, to close down State Hospitals and the larger Intermediate Care Facility/Mentally Retarded (ICF/MR) Facilities. The ARCs no longer represent Parents with Children in State Hospitals although this was one of their Charter functions.

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- *Retired, Vice President, General Mills, Inc.*
- *A Founder and Past President, ARC Hennepin County & ARC Minnesota*
- *Two-term director and first fund raising chairman, ARC US*
- *A Founder and Administrative Board Member, Camp Friendship*
- *Six Years, Director of the Welfare Council, Community Chest*
- *Six Years, Director of Hammer School, Wayzata*
- *Eight Years, Chairman, Annandale MN School Board*
- *Two terms, Member of Governor's Advisory Council on Special Education*

AN OPEN LETTER TO STATE LEGISLATORS ...

RE: Quality of Patient Care and Closing State Hospitals

Thirty-five years ago, after seven years of struggle and grief, we placed our profoundly retarded son, Peter, in the Faribault State Hospital. Today we still say, *"This was the right decision."*

Four former ARC presidents still have their child at the Faribault State Hospital. All favor continuing placement.

During 1983 and 1984, mentally retarded residents of our State Hospitals had placement reviews in county district courts as per the Commitment Law. In the vast majority of cases the judges ruled in favor of continuing placement because of the adequacy of care and the absence of equally good care available in the community.

When asked, parents overwhelmingly favored continuing placement as did the County Case Workers.

Most professionals support the *"Continuum-of-Care"* approach, which includes State Hospitals; so that various levels of Health Care are available to best serve the needs of Mentally Retarded people, so as to provide them, their physicians, case workers, parents, and guardians with viable options of care.

This view was presented to State legislators at a 1984 hearing by a Hennepin County social worker. Senator Dave Durenberger, Chairman of the Senate Finance subcommittee on Health, has written about his support of State Hospitals as part of the *"Continuum-of-Care"* approach and is against S2053, the federal bill which would phase out State Hospitals by withdrawing their Medicaid funding.³

Thousands of people attended the Town Meetings conducted by The State Planning Agency, and voiced strong support for our State Hospital system. As reported by The Agency, PATIENT CONCERNS were the top issues discussed.⁷ To quote one paragraph,¹

"Relatives and friends of State Hospital residents spoke of fears relating to possible dumping, shuffling residents from hospital to hospital, quality and stability of community care, and the need for specialized supervision for individuals who are medically fragile."

Care in Minnesota State Hospitals has improved dramatically over the past 15 years. The Faribault and Willmar State Hospitals are fully accredited. All State Hospitals are licensed under the same standards as apply to community based ICF/MR facilities.

In spite of all of this, a small hand full of Ideologues continues to make significant progress in their drive to shut down State Hospitals or to curtail the number of people served. They argue Human Rights theory and offer Pie-in-the-sky concepts of community care which don't exist. The thousands of State Hospital supporters who showed up for the Town Meetings, know, from their own experiences what are the crushing responsibilities of around-the-clock care, seven days a week, year in and year out.

Other Ideologues, using the same arguments, advocated the mass release of Mentally Ill persons from State Hospitals, opposed long-term care, and called for community-based care. Once the releases were effected, the community care was not forthcoming. The result is that today, we have a National disgrace.

As reported by THE U.S. NEWS AND WORLD REPORT:

"Hardly a section of the country has escaped the presence of ragged, ill, hallucinating human beings, wandering through our city streets, huddled in hallways, or sleeping over vents.

"The police chiefs of Minneapolis, Denver, and New York state that 30-50% of their homeless street people are mentally ill. Others estimate that 50% of the poor in the USA are either Mentally Ill or Heads of single family households.

"Hardly a section of the country has escaped the presence of ragged, ill, hallucinating human beings, wandering through our city streets, huddled in hallways, or sleeping over vents."

The police chiefs of Minneapolis, Denver, and New York state that 30-50% of their homeless street people are mentally ill. Others estimate that 50% of the poor in the USA are either Mentally Ill or Heads of single family households.

When the Dixon State Hospital of Illinois was shut down, the result of Ideologue advocacy, many of the Mentally Retarded residents were moved into run down Hotels in the Chicago Loop where they quickly became victims of Chicago street hoodlums.

The only hard data offered by the Ideologues are unrealistic depopulation schedules. One has emerged from the Federal District Court Consent Decree. But the court monitor, talking out of both sides of his mouth, warns that the Consent Decree does not condone substandard care. The other is the depopulation schedule proposed by the Department of Human Services.

County commissioners are reacting to these plans by saying, *"Show us your money and then we can plan for community care. We aren't raising county taxes to pay for your schemes."*

The current Commitment Law is the result of Ideologue advocacy. The law makes it very difficult to admit someone to a State Hospital. It has the practical effect of reducing the resident population through attrition rates which are higher than the very low admission rates. One tragic result is that the very few community based facilities that can accommodate severely retarded multiple handicapped people now have long waiting lists. In the meanwhile, beds are available but not occupied in State Hospitals because, to quote a spokesman, *"We aren't supposed to admit such people anymore!"*

During this session, you legislators, once again have the opportunity to protect the mentally retarded residents of our State Hospitals from the tragic results of senseless ideology. With State Hospital care as good as it is, there obviously is no need to take hasty action based upon flawed planning. If residents can be better cared for in other ways — and this has yet to be proven — so be it! But if changes are to be made, please make them in an orderly, planned, proven, evolutionary way.

Sincerely,



John L. Holahan

SUMMARY AND RECOMMENDATIONS

Continuum-Of-Care...

Today, Minnesota has a CONTINUUM-OF-CARE system for providing for the needs of Mentally Retarded Persons.

The system has evolved to include a variety of components. Three important ones include:

State Hospitals operated by the public sector...

For Profit ICF/MR community based facilities...

And Non-Profit ICF/MR community based facilities operated by the private sector.

People who use these components give them high marks.

Each provides services for people with different degrees of handicaps so that movement of residents between the facilities is **greatly restricted** if Quality of Care is to be maintained.

There is no urgent need to make drastic changes in the Continuum-Of-Care system without giving the subject serious thought, careful planning, and trials with pilot experimental facilities.

Current Dangers – The Ideologues ...

Supporters of the Continuum-Of-Care system are totally opposed to ideologues who want to do away with State Hospitals and ICF/MR facilities by first moving residents from State Hospitals into ICF/MR facilities, moving ICF/MR residents into small family size limited resource facilities, and finally ending up only with the latter.

The Ideologue proposals make Human Rights the key issue rather than Quality-Of-Care. They promise miracles of short term care and turn their backs on long term care.

They would push mentally retarded persons into situations similar to those foisted onto Mentally Ill persons.

The mass indiscriminate dumping of mentally ill persons out of State Hospitals and long term facilities into communities which provide few facilities and grossly inadequate services is a National and Minnesota disgrace.

And yet, the process to repeat the disaster with Mentally Retarded persons is under way. Tactics currently in use include:

- Depopulation schedules for dumping residents out of State Hospitals.

- A very stringent Commitment Law which makes it very difficult to admit a person to a state hospital.
- Recommendations being submitted to the 1985 legislature which would:

Reduce staff in State Hospitals caring for Mentally Retarded persons on the basis of the declining number of residents brought about, not by lack of need, but by the tactics of Easy-To-Dump-Out and Very-Hard-To-Get-In.

Make the Commitment Law even more restrictive than it now is.

Planning Made Easy ...

A declining resident population in State Hospitals follows from the tactics of Easy-To-Dump-Out and Very-Hard-To-Get-in.

Planners who only crunch numbers and don't have to face up to Quality-Of-Care issues have an easy time of it.

If one doesn't ask *why* the resident population is shrinking, one looks at the numbers, cuts budgets, cuts staff, and favors closing down state hospitals.

What Must Be Done...

The dumping process must stop.

Quality-Of-Care must become the Issue.

The Depopulation Schedules must be challenged through legislative action or in the courts.

The Commitment Law must be changed to accommodate reasonable needs for State Hospital placement.

The Continuum-Of-Care System must be preserved.

How Serious Is The Issue ...

The Ideologues and Supporters of Minnesota's Continuum-Of-Care System are in total disagreement.

Their disagreements are analogous to those which prevail on the Abortion Issue.

What Is A Legislator To Do ...?

Make haste very slowly.

Refuse to make changes in the present day Continuum-Of-Care system until more factual information is developed and Quality-Of-Care concerns are resolved.

(NOTE: There will be no consensus to support! Legislators must rely on their common sense rather than submitting to the tactics of single issue pressure groups.)

SUPPORTING STATEMENTS

1. *Continuum Of Care ...*

Today, Minnesota has a CONTINUUM-OF-CARE system for providing for the needs of Mentally Retarded Persons.

The system has evolved to a variety of components. Three of the most important include: *State Hospitals* operated by the public sector. For *Profit* and *Non-Profit ICF/MR Community based facilities* operated by the private sector.

In the past, the State has worked effectively with the private sector to produce a good system of care for those using these three components. People who use them give them high marks.

The Continuum-Of-Care system includes other types of facilities, and should include the very small, limited resources facilities favored by the Ideologues. Mentally Retarded persons living in their home communities always have, and always will, greatly outnumber those who are residents of State Hospitals and ICF/MR facilities. The ratio is from 6 to 1 to 17 to 1 depending on how many mentally retarded persons one chooses to say there are.

State Hospitals are crucial to the Continuum-Of-Care approach. Most state hospital residents are severely or profoundly retarded with other severe handicaps-physical, medically fragile, behavioral, and learning.

Most professionals support placing such people in state hospitals where necessary long-term care is provided. This is the unique function of state hospitals.

County Case Workers have so testified at a 1984 legislative hearing.

Senator Dave Durenberger, as chairman of the subcommittee on Health of the powerful Senate Finance Committee has conducted in-depth studies and hearings on S2053, the bill which would close down State Hospitals by gradually withdrawing their Medicaid funding. Durenberger has written to a parent of the Faribault State Hospital stating that he does not agree with S2053, and favors state hospitals as part of the "*Continuum-Of-Care*" approach which he strongly supports.³

Senator Rudy Boschwitz has also written stating that he believes shutting down State Hospitals would downgrade the Quality of Care available to handicapped people and opposes S2053 for that reason.⁴

2. Critical Differences . . .

Residents — State Hospitals — ICF/MR Facilities

Figure (1) and Figure (2)^s clearly show the differences between residents in ICF/MR Facilities and State Hospitals. The most severely disabled people are in State Hospitals. Sixty percent are profoundly retarded. Less than one-third are capable of self help. Two-thirds need help in toileting, eating, dressing and grooming.

Other data shows that the For-Profit ICF/MR Facilities have selected residents with the least mental retardation and most capable of self help. In short, they have selected residents who require the least help. The Non-Profit ICF/MR facilities are somewhat in the middle. They have residents who require the least help but also have a significant number of residents who are severely retarded and have lesser self help abilities.

These differences can be shown another way. Facilities are licensed according to whether or not they can accommodate residents who are ambulatory and capable of self-preservation,(5) Class A facilities house residents who can leave on their own in case of fire. Class B facilities house residents who cannot. Figure 3 tabulates residents by this classification.

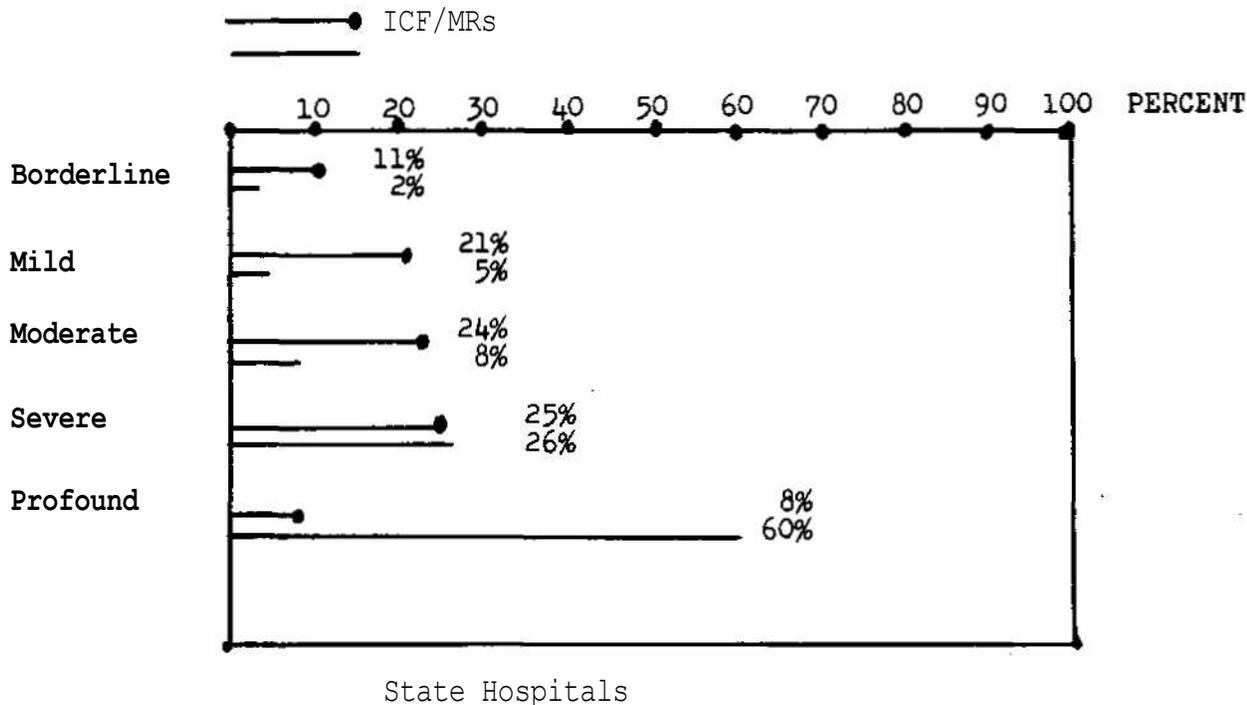
-FIGURE 3-
Residents Classified By Self-Preservation Ability (A)
... Or Not (B)

| TYPE OF FACILITY | NUMBER OF RESIDENTS <i>(Licensed Capacity)</i> | |
|--|---|-------|
| 8 State Hospitals | Class A | |
| | Class B | 2,250 |
| Non-Profit ICF/MR 142 Facilities..... | Class A | 1,103 |
| | Class B | 695 |
| For-Profit ICF/MR 179 Facilities..... | Class A | 2,686 |
| | Class B | 1,167 |

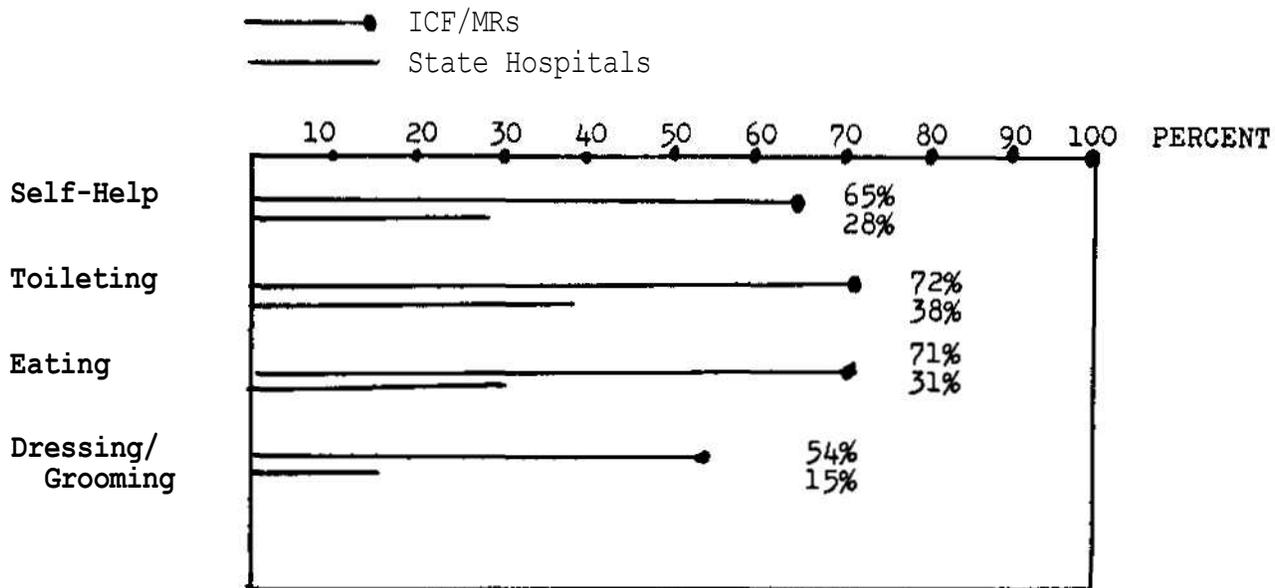
The fact that residents are placed in facilities according to the severity of their handicaps is not a negative. For most of the past fifteen years there has been effective cooperation between the concerned individuals; residents, State Hospitals, the Department of Welfare, Parents, County Case Workers, ICF/MR Operators, and Legislators. Significantly, the Care of Mentally Retarded persons has never been subjected to partisan politics. The net effect has been an evolutionary change, a generally orderly and planned movement of residents out of State Hospitals into community facilities, which were built/modified and staffed to provide adequate services for the kind of residents they were to receive.

By and large the movement has benefited residents except in a small but significant number of cases. In these instances, residents have not been properly placed and have been transferred back to State Hospitals.

—Figure 1—
**RETARDATION LEVELS IN ICF/MR FACILITIES
 AND STATE HOSPITALS**

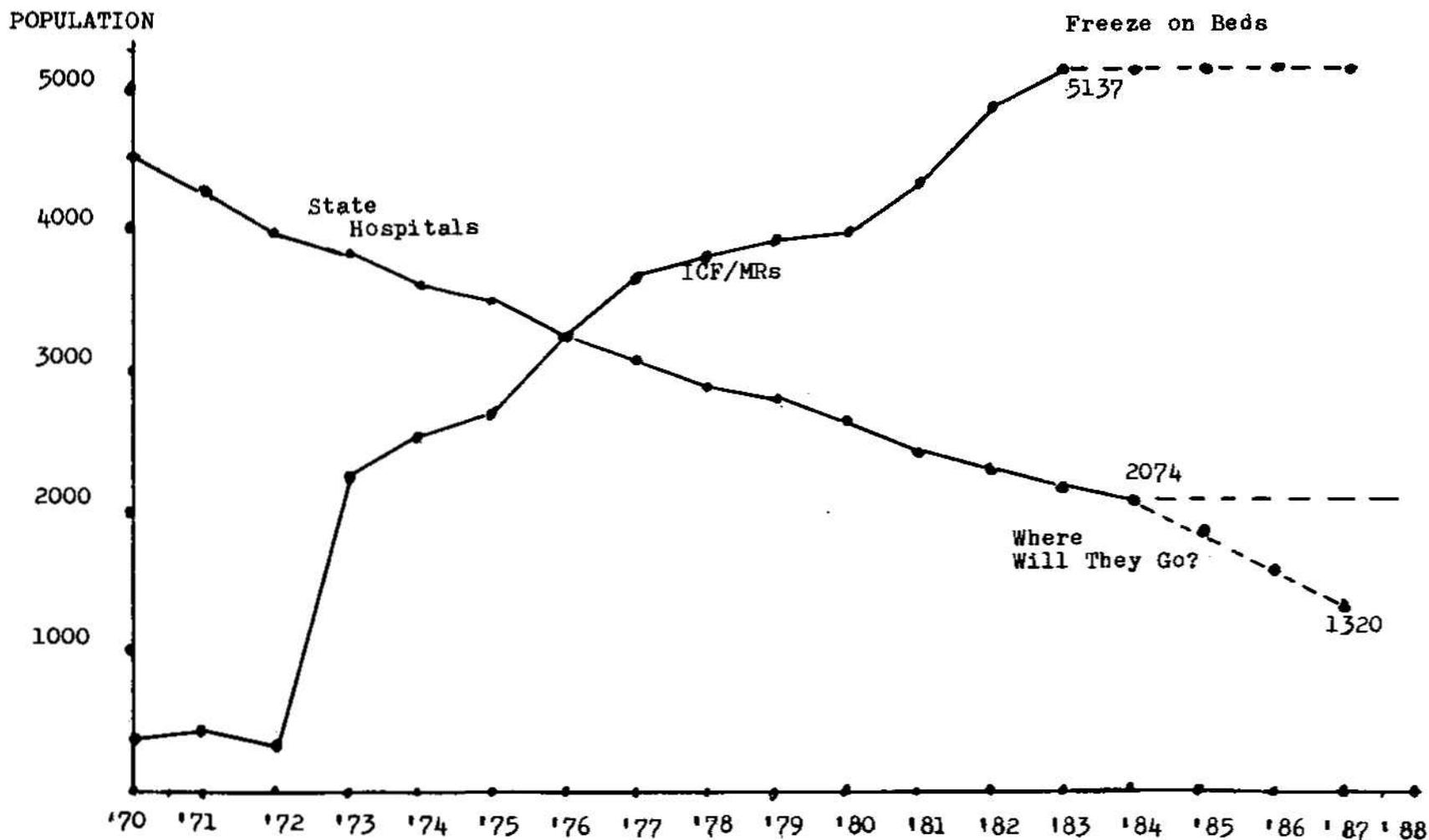


—Figure 2—
**INDEPENDENCE LEVEL IN ICF/MR FACILITIES
 AND STATE HOSPITALS**



—Figure 4—

RESIDENT POPULATIONS • STATE HOSPITALS AND ICF/MRS



Approximately five years ago this evolution in the Continuum-Of-Care system began to be disrupted by the Ideologues. They take the position that only they know how to take care of all mentally retarded persons including the residents of State Hospitals and ICF/MRs. Significantly, few of the Ideologues have ever taken care of people like State Hospital residents and simply do not understand what it is like to take care of a highly dependent individual 24 hours a day, seven days a week, year in and year out.

Thanks to the Ideologues, we have, today, serious problems in the Continuum-Of-Care system. Please refer to Figure 4 to follow the explanation of the problem.

Figure 4 plots the increase in ICF/MR beds and the decrease in State Hospital beds. As the ICF/MRs geared up to handle the state hospital residents with the lesser handicaps their beds increased. Also, many parents elected to place their children in such of these facilities as could accommodate them. Likewise, the number of residents in state hospitals decreased as the ICF/MRs increased in numbers and could accommodate the residents with the lesser handicaps.

The Ideologues take the very strong position that the Continuum-Of-Care system is no longer acceptable - State Hospitals and ICF/MR facilities should be phased out of existence. Thus we have today a series of tactical measures in effect, which, if their trend lines continue, will effectively destroy the system as we now know it. The tactical measures include:

1. A freeze on the number of ICF/MR beds. Note the dotted line on the ICF/MR plot, figure 4.
2. Depopulation schedules, one of which is part of the Consent Decree, and one of which is a schedule from the highly flawed Department of Human Services Waiver Services plan. Note the dotted line on the State Hospital Plot, figure 4.

3. The Commitment Law which makes it very difficult to be admitted to a State Hospital...

It can be seen that the Depopulation schedules for State Hospitals (*the dotted line on the State Hospital plot*) would move people out of State Hospitals at a faster rate than was done in the past when there were ICF/MR beds being made ready for carefully selected residents. **Today, with the Freeze on ICF/MR beds there is no place to go. This is what "Dumping" means.**

The situation is even worse knowing that current residents are those who are left; those who have not been selected in the past to go out into the community or into ICF/MR beds; those who are severely (26%) and profoundly (60%) retarded with other severe handicaps; two-thirds of whom cannot help themselves, cannot attend to their toileting, feeding, dressing and grooming; all of whom would perish in a fire if not led to safety.

One immediate result of the current trends and upsets in the Continuum-Of-Care system is the development of long WAITING LISTS of persons with severe mental retardation and other handicaps trying to be admitted to Non-profit ICF/MR facilities. The State Hospitals have the beds, staff, and so on, but go unused because *"Such people are not supposed to go there.*

Today, most of the persons admitted to State Hospitals are persons who are rejected from community and ICF/MR facilities. Many of these people are former State Hospital residents who were transferred into the community and moved from facility to facility in the hope; of finding a suitable placement. The experience is very traumatic for all involved and is one of the many reasons why parents of State Hospital residents are so negative about community placement. With State Hospital care as good as it is why be a voluntary party to such reckless social experimentation.

4. Quality Of Care ...

In general, parents, guardians, and case workers are satisfied with the care that mentally retarded residents are receiving in the Community Based ICF/MRs, and in State Hospitals.

For example: The children of four past ARC MN presidents live at the Faribault State Hospital. These past presidents speak highly of Faribault and want their children to continue living there.

During 1983 and 1984, mentally retarded residents of the State Hospitals had placement reviews in county district courts as per the Commitment Law. In the vast majority of cases, the judges ruled in favor of continuing placement because of the adequacy of care and the absence of equally good alternative care elsewhere. This was true even in Hennepin County where residents, for the most part, were represented by court-appointed attorneys who were highly biased against state hospital placement.

At these reviews, when asked, the large majority of parents stated their wishes for continuing placement in the State Hospital.

At these reviews, most of the case workers, recommended continuing placement at the State Hospital.

The three types of facilities all operate under the same ICF/MR licensing criteria, and are largely financed through Medicaid funding.

State Hospitals may apply for Accreditation, meeting the more demanding standards of the Accreditation Council for Mentally Retarded and Developmentally Disabled. Two State Hospitals, Faribault and Willmar have received this Accreditation.

At the Town Meetings called by the State Planning Agency to obtain testimony on the impact of closing State Hospitals on employees and communities, RESIDENT AND PATIENT CONCERNS were the top issues discussed.⁷

*"Relatives and Friends of state hospital residents spoke of fears relating to possible 'dumping', shuffling from hospital to hospital, quality and stability of community care, and the need for specialized medical supervision for those individuals who are medically fragile."*¹

The surprising large volume of mail received by the U.S. Senate Health subcommittee of the Finance Committee against S2053 ran very heavy against the bill because, as written, it would phase out both State Hospitals and Community-Base ICF/MR facilities by denying them Medicaid Funding. The mail reflected the same fears as were voiced at the Town Meetings.

Statements about the Quality of Care in the small family-sized limited resource facilities so favored by the Ideologues are difficult to make. (*See Section 8*) There is yet no functional description of what these facilities can or cannot do. It would be highly desirable for a few of these facilities to be put into experimental operation, operated by competent researchers, so as to acquire demonstration data which will show what these facilities can do.

For *example*: Before "We" recommended legislative support and funding for Developmentally Disabled Classrooms, "We", for over 10 years, carried on demonstration projects at Sheltering Arms and Elliot Park Neighborhood House to ascertain what could be accomplished. We did not recommend a theory. In fact, the Ideologues have been severely critical of Dr. Harriet Blodgett, the Director of the Sheltering Arms project because she would not make recommendations beyond what she was able to support with her experimental data.

The bottom line is this: Current depopulation schedules and the resulting recommendations to cut back state hospital staffs means dumping state hospital residents out into communities who have made no provisions for their care. Today, communities are loaded up, with waiting lists, caring for retarded people now in the communities.

Today there is a new situation of alarming proportions developing, that of babies born highly defective and kept alive by heroic measures in community hospitals. When it comes time for the baby to be discharged, there is no place to go; no community facility that provides the special care given in the hospital.

5. *The ideologues ...*

Webster's dictionary defines "Ideology": *1. A political or social philosophy, esp. of a certain class. 3. Theorizing; impractical thinking. Ideologues are those who practice their Ideology.*

Today it is popular to talk about Normalization. The Normalization principle, simply put, says that handicapped people are entitled to the same rights and life styles as the rest of us have.

The Ideologues argue that since none of the rest of us live in Hospitals and the larger ICF/MR facilities, why should mentally retarded people be required to live like this.

We who support State Hospitals and ICF/MR facilities say:

These residents, because of the degree of their mental retardation and other handicaps-physical, health care, learning, and behavioral, require around the clock attention, seven days a week, year in and year out and this degree of intensive care cannot be given in very small family-sized facilities with very limited in-house resources.

Who are the Minnesota Ideologue Leaders? They include . . .

Some staffers, Governmental Affairs Committees, and some directors of various ARC units, especially ARC MN. The controversy rages within the ARCs and is causing severe internal problems. The ARCs no longer speak for parents with children in State Hospitals.

... The Legal Aid attorneys who were the plaintiff attorneys in the WELSCH vs. NOOT lawsuit out of which came the CONSENT DECREE and its Depopulation Schedule.

. . . The Court Monitor who oversees the enforcement of the Depopulation Schedule. The last monitor issued warnings that persons must not be moved into inferior care facilities when they are transferred out of State Hospitals.

. . . Department of Human Services officials who keep coming up with Depopulation Schedules.

. . . The panel of attorneys who represent Respondents {Faribault State Hospital Residents) in Hennepin County District Court. The court is processing the appearances and hearings mandated by the Commitment Law.

The Ideologues have one considerable advantage over the Supporters of State Hospitals. The Ideologues, for the most part, are employees on public or non-profit payrolls and expense accounts. Their employers allow them to spend up to full time on legislative and regulatory issues which will lead to closing down state hospitals and ICF/MR facilities. The Ideologues are well acquainted with each other and work together. They are to be commended for their influence and effectiveness!

The Supporters, on the other hand, so far, are people who must earn their living in other ways. They cannot spend the required time to keep track of and counter what the Ideologues are doing. Only the AFSCME Council 6, the union of State Employees, has several staffers available to spend limited time countering the moves of the Ideologues. The Ideologues discount Union Employee statements on the basis that Union Employees are only interested in protecting their jobs. On the contrary, we have found them to be far better informed about and far more dedicated to caring for mentally retarded persons than are the Ideologues.

Thus it is that The Supporters, who far outnumber the Ideologues, must make their points via Town Meetings and mail to legislators; and not via carefully staged public hearings, carefully crafted lobbying efforts, and time consuming lawsuits and legal procedures.

Unfortunately, the efforts of the Supporters lag those of the Ideologues. The Ideologues strike first, and then the Supporters respond as best they can.

Ideologue Accomplishments to date include:

- *The Commitment Law*
- *Depopulation Schedules*
- *The Waiver Service Plan*
- *The Consent Decree*
- *Breaking apart the United Front which was once behind the Continuum-Of-Care approach to caring for all mentally retarded persons.*

EXAMPLES:

- State Hospital Employees and Department of Human Services Officials have many sharp differences.
- State Hospital Employees are constrained from making any public statements on issues pertaining to care of mentally retarded persons; their feelings about the department; their feelings about the Ideologues -- especially about the ARCs.

- State Hospital Employees can and do speak out via their union, AFSCME, Council 6. The standard rebuttal, "*The Union is only out to protect the jobs of their members.*"
- Current Union proposals⁵ for widening the scope of State Hospitals is being opposed by ARC MN and ARRM. (12) In years past, these groups worked together, not against each other.
- It is obvious that continuing heavy handed treatment of State Hospital employees from within and without results in poor morale and increasing labor unrest. Perhaps this is another tactic to hasten closing down state hospitals.
- As State representative Peter Rodosovich said,¹³ "*State Hospital employees work in a "fishbowl" where accomplishments are recognized sometimes and mistakes recognized all the time.*"
- ARC members are at odds with each other. "We need another organization" is a common cry. Two new National organizations have been formed; PARENTS NETWORK and CAR. The new organizations promote the functions the ARCs had when they were first organized, namely to build and broaden The Continuum-Of-Care system.
- Many County Human Services Departments and County Commissioners are in open disagreement with the State Department of Human Services Ideologues and the other Ideologues as well. They are being asked to support schemes like Waiver Services for which they have neither funds nor staff.
- There is increasing ill-will between ARCs and ARRM members.

6. Parent Rights ...

The rights of parents with children in state hospitals are becoming ever more obscure. There is an assumption that parents give up their rights when they consent to having the State become the guardian of their children. This is wrong. The Law does not state that! Years ago it was recommended that parents place their children under State guardianship to protect the children when the parents died.

Many residents in State Hospitals do not have parents available to represent them. Parents have died. Many of the residents are middle-age and older.

Persons who say they are AN ADVOCATE are allowed to represent residents. They are allowed access to patient files. The Department of Welfare has even taken the remarkable step of stretching the definition of PARENT to include AN ADVOCATE even though they do not define AN ADVOCATE.

Thus you have the ridiculous and confusing spectacle of Peter Holahan's parent, John L. Holahan, arguing before judges, social workers, and legislators to keep Peter in the Faribault State Hospital and his ARC ADVOCATE arguing to have him placed in an inappropriate community facility.

Advocacy, as practiced by the ARC's, isolates state hospital residents from the very people who do the most as though only they have no conflict of interest. In fact, their advocacy has only one simple purpose: To get residents out of state hospitals (*regardless of the consequences*).

In my mind, there is no longer any doubt that the Ideologues intend to by-pass parents. These people, on non-profit or public payrolls, devote their working hours to their social manipulations. Parents have to earn a living and cannot devote the same thought and hours to watchdog over what these manipulators of public policy are up to. The net result is that decisions affecting their children are made without parents being consulted.

I have repeatedly asked Department of Human Services officials about what are the rights of parents in matters which affect their children. I do not get clear cut answers, primarily, because I don't think these people know. My conclusion is that a parent can show up at a policy meeting, but there is no mechanism or intent to tell him in advance about the meeting.

Involving the ARC Advocates and Ideologues is not the same as involving parents with children in State Hospitals.

7. The Commitment Law . . .

The Commitment Law is an effective tactic to Close-Down State Hospitals for both the Mentally Ill and the Mentally Retarded.

It has the practical effect of making admission so difficult that the attrition of resident population through death and dumping into inadequate community facilities greatly exceeds new admissions. Thus, Ideologues, State Planning Commissions, Department of Human Services Executives, and whoever need not concern themselves about the Quality-Of-Care in the Community.

Instead, one can accept unrealistic Depopulation Schedules and only look at declining resident populations, and cut state hospital budgets and staffing accordingly. Like taking an anesthetic, one needs feel no pain. One needn't get into the Quality-Of-Care issue as the mentally retarded residents are dumped into inferior community facilities.

The law is vague as to implementation so that each county executes it as befits their resources. The law makes it easy to by-pass parents.

The actual workings of the Commitment Law, at least in Hennepin County is an example, I cite my own experience because other parents have told me about similar experiences.

Because I knew a Commitment Hearing was to be held, I kept checking with Hennepin County as to the date. I called in on Thursday, January 19, 1984 and was told that the Hearing was for Monday, January 23rd. Also, a new case worker had been assigned to Peter, for the hearing. So many hearings were scheduled that the regular case workers could not handle the load. The new case worker thought the court might have appointed an attorney out of the pool to represent Peter. I told her that I would hire an attorney. I didn't want Peter to be represented by a person unknown to me. The next day, Friday, I contacted the attorney of my choice, a man experienced in these matters, and he agreed to handle the case. On Saturday, I visited the Faribault State Hospital and was shocked to find out that the pool attorney and an ARC Advocate, newly hired, were going through Peter's records. At the hearing, the pool attorney tried to repre-sent my son against my wishes and told the judge that I was too biased to properly select an attorney who could objectively represent my son. The judge was not impressed with this argument and pointed out that the law gives parents the right to hire an attorney to represent their children in a commitment hearing.

Another parent solved the problem by hiring an attorney to represent him at the hearing, so that his views could be expressed to the court.

Currently, about two-thirds of admissions are for residents who were previously placed out of State Hospitals into community facilities; only to find that these facilities could not take care of them, and re-admission was the only viable option remaining. In the meanwhile, the hospital resident suffered the considerable trauma of a displaced person; shifted from one community facility to another, and cared for by ever changing personnel.

Community Facilities are at liberty to select their residents and can discharge them as they choose. State Hospitals must accept whoever is directed to them by the courts.

During the 1985 legislative session, the Ideologues are seeking another change to the Commitment Law, a provision that an admission to a State Hospital for care of Mental Retardation is valid for only one year, that the Commitment Hearings must take place every year. This is a subtle form of harassment.

At the very least it will require about 2,000 new hearings per year. It will cost parents or taxpayers, when pool attorneys are used, another \$1 million dollars per year in legal fees, and serve no useful social purpose.

Attorneys refer to the Commitment Law as it now stands as THE ATTORNEY WELFARE ACT. The new changes, if enacted, will provide even more attorney welfare!

8. Some Questions About Small Community Facilities For Current State Hospital Residents ...

The Ideologues advocate caring for all Mentally Retarded persons in small family-size community based facilities which, by definition cannot match the resources of the State Hospitals.

The theory is that the lack of in-house resources can be provided from the general resource pools that exist in the community, or that the needed resources will be added by the community.

With the Mentally Ill, this hasn't happened. Most counties provide few services to help the mentally ill. Even Hennepin County, which has added resources to help the Mentally Ill, doesn't begin to have enough. The TV Documentary stated that the resources are so varied and so uncoordinated that it is more a function of luck than the result of planning when a Mentally Ill Person happens to come into a facility that can help.⁸

The Ideologues seem to reject the fact that mentally retarded people now in State Hospitals, require long-term care, not short bursts of either respite care or curative care. Almost all of the community care programs for the Mentally Ill have the same defect. They offer short-term care, as though there is no such thing as a mentally ill person who needs long-term care.

The Department of Human Services Waiver Services plan is inclined in the same direction. This plan unfolds around an Ad Hoc committee convened by a *County Human Services Group*. The committee would consider the care requirement posed by a given mentally retarded person and study bids for care submitted by small community based facilities. If there was a match between services required and services offered, the retarded person would be placed.

At a Waiver Services workshop(9) called by ARRM so the DPW officials could explain the Waiver Services plan, the question repeatedly asked but never answered was, "*Are we talking about long-term or short-term care?*"

The Waiver Services Plan has a three year term, and yet the Depopulation Schedules stretch out for longer periods.

Yet, the Ideologues and the Department of Human Services (*new name*) offer small facilities as the preferred provider of Waiver Services to take care of the current residents of State Hospitals.

The State Planning Commission, and the Board of Commissioners to whom they report, do not address the Quality-Of-Care problem, since that was not in their study charter, and simplistically take the Depopulation Schedules and use them as the basis for predicting smaller resident population. They recommend staff cuts to match the declining populations.

When Ideologues come before legislators, because of time constraints as well as tactics, they talk generalities, not specifics.

For *example*: Currently there are about 7100 mentally retarded persons being cared for as follows:

2100 in seven State Hospitals

5000 in about 400 Community Based facilities(5).

Were all of these people to go into small family-sized facilities, as recommended by the Ideologues, some 1200 facilities would be required, of households of six residents.

Such a conversion is frightening to contemplate if it is done without adequate planning and advance pilot experiments.

Some of the many questions raised by ARRM people, state hospital employees, parents, county case workers, and others include:

- *What will be the Quality Control program to license and monitor these facilities to assure proper Qualify -Of- Care?*
- *If this is to be the responsibility of County Social Workers as part of their case load, will the counties add the required case workers?*
- *What sort of buildings will be required?* The ordinary single family home or apartment is totally unacceptable for many state hospital residents . . .

Residents with behavior problems would quickly smash windows, break furniture, and pound holes in the all too common plaster board walls. Plumbing and electrical wiring are unsuitable. Fire code standards are much more stringent for facilities housing Class B residents.

- *How will some of the following problems attendant to small facilities be overcome?*

High staff turnover due to low pay and few benefits.

Inadequate staff training.

No backups to cover sudden resignations.

Relative to State Hospitals, slow and inadequate support services such as health care, psychological, and so on.

Burn out of in-charge personnel who must cover the deficiencies.

Pressures to accept high-care patients either for financial reasons or to accommodate social workers who are under pressure to find spots for State Hospital residents so as to meet the unrealistic depopulation schedules.

- *Where will the money come from?* This is the first question being asked by County Commissioners. They say, "Show us your money and then we can plan for Community Care. We aren't raising county taxes to pay for your schemes."

The Ideologues suggest that the money will come from that saved by moving residents out of state hospitals. Just recently an "expert" from Rhode Island" came to Minnesota to advise ARC MN and the Department of Human Services on this point. He told them that it simply wasn't true that the switch to small facilities could be paid for this way. Considerable sums of money will be required.

Finally we ask this fundamental question:

- *Should the State get completely out of operating direct care facilities for certain types of handicapped people, including mentally retarded people? Should the State function be confined to licensing and funding?*

The answer, of course, is debatable. No country in the world has turned over the care of mentally retarded people completely to the private sector. The Minnesota experience clearly shows that the Continuum-Of-Care system works with an evolutionary mix of State and private operations. The system was at its best when the providers worked together.

Now, thanks to the Ideologues, we have no consensus about anything. Parents are worried sick over what might happen to their sons and daughters now adequately cared for in State Hospitals. Younger parents are worried sick over the tack of community facilities and the long waiting lists to get into facilities that can handle high care, low functioning multiple handicapped children.

9. Costs ...

The original thrust behind Waiver Services and S2053 is that claim that State Hospital Care is far too expensive and that Community-Based care, even in ICF/MR facilities, will be less expensive, especially if provided in the small, family-sized, limited resource facilities.

A series of recent studies by the Office of the Legislative Auditor and summarized by the ARRM (12) report supports such statements. The ARRM analysis, however, does not include the cost of Developmental Services, Health Care costs, Transportation costs, Inspection costs, and Case Work costs which are all part of the infra-structure of services which back up Community Facilities, and without which, Community Facilities cannot be licensed. The AFSCME report(5) takes the same data and concludes the costs are about the same when total costs are compared. State Hospital costs include the infra-structure costs because they are all provided from within. Community facilities, for the most part, send their residents outside for the infrastructure services.

Note that an ICF/MR facility cannot be licensed unless there are provisions for obtaining the infrastructure services.

The Ideologues, take a strong position against any facility which provides these infra-structure services in-house.

The Auditor figures do show a sharp increase in State Hospital costs beginning in 1981. This is the direct result of the CONSENT DECREE which applies only to state hospitals and burdens them with staffing and care requirements not imposed upon community facilities. It follows that the CONSENT DECREE requirements are too stringent for State Hospitals, or that similar appropriate requirements should be imposed on Community Facilities. The court monitor is uneasy about community standards.

We have previously pointed out that state hospital residents are high care people compared to those living in the community. Obviously, it costs more to take care of them. It is highly significant to note that state hospital residents, for the most part, are those who were left. The lower care residents were those selected for community placement.

Recently, I was given cost figures for two state hospital residents who were transferred into community facilities. It was estimated that the one resident would cost the community \$250 per day, the other, \$400 per day, for comparable care to what had been provided by the State Hospital. I cannot cite a reference for these numbers in order to protect the people who gave me the information.

In short, when we compare comparable services and Quality-Of-Care we obtain comparable costs.

The cost problem, if there is one; in State Hospitals is clearly a matter of COURT ACTION and PATIENT SELECTIVITY.

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