ALTERNATIVES

CHOICES AND CONCERNS

A POSITION PAPER

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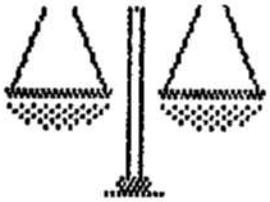

Governor's Planning Council
on Developmental Disabilities
Minnesota State Planning Agency
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658 Cedar Street
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developed by the

Minnesota Chapter

Congress of Advocates

for the Retarded, Inc.

CONCERNS

SMALL IS NOT BEST

"PARENTS BYPASSED"

"HOLD THE LINE ON STAFF CUTS AND ON THE DEPOPULATION OF STATE REGIONAL CENTERS UNTIL A FAIR AND THOUGHTFILLED MN STATE PLAN IS DEVELOPED"

"FAIR COST STUDIES MADE"

So now, who speaks for us? Until a few weeks ago, NO ONE!

The ARCs (Association for Retarded Citizens), which we helped found, no longer speak for parents whose children live in Minnesota's Regional Treatment Centers (RTCs).

Neither has the past leadership in the Department of Human Services.

Neither do the attorneys who represent the District Court and planned the Consent Decree.

Today, 39 years later, we find ourselves, once again, alone.

To express our opinion, we have now formed the Minnesota Chapter of the Congress for the Retarded, Inc., and through it, we now speak. Our collective voice carries the weight of nearly 40 years of experience.

We are no longer alone.

Deinstitutionalization - Is our opinion important?

There is a race afoot. This race is being run neither with rules nor a finish line. If there is a finish line, its position appears to change from time to time, though mostly from administration to administration.

This race is one in which our children are barely participants. The runners are politicians, administrators, and advocacy groups. The questions and concerns of parents were not tendered before the race started and are not now being given credence with the race underway.

The name of this race is DEINSTITUTIONALIZATION. Some advocacy groups such as ARC of Minnesota believe that everyone should blindly embrace this concept, carry out its implementation statewide, and worry about its consequences after the fact. They believe that they have the right to determine what is best not only for their child, but for all children.

The Minnesota Chapter - Congress of Advocates for the Retarded, Inc. is deeply concerned that deinstitutionalization in the State of Minnesota (both in policy and practice) jeopardizes a system of choice with its "one size fits all" notion of normalization.

In this position paper, the Minnesota Chapter of the Congress of Advocates for the Retarded, Inc. will discuss some of the grave concerns that we currently have about deinstitutionalization in the State of Minnesota and concerns recently highlighted in the Governor's budget request.

During this session, you as a legislator, once again have the opportunity to not only maintain, but to promote a system of choice, that allows us as parents and advocates to utilize services in both the public as well as the private sector for our mentally retarded children. We ask that you read our position paper carefully, and help us develop this system of choice that in the words of Pat Cook, Homeward Bound President, "evolves not only from your vision and commitment as our leaders; but takes into consideration, seeks out, hears, listens to, and is finally shaped together by the needs of families across the State of Minnesota who are after all the ones really challenged by the handicaps of their sons and daughters."

Sincerely yours,

Norman K. Bailey

John L. Holahan

Norman K. Bailey
President
Morton, MN

John L. Holahan
Parent & Member
Annandale, MN

AN OPEN LETTER TO STATE LEGISLATORS ON

ISSUES RELATED TO THE QUALITY OF RESIDENT CARE:

The Role of Regional Treatment Centers

Prepared by

the Minnesota Chapter - Congress of Advocates for the Retarded, Inc.

Who Speaks For Our Children?

The birth of a child brings with it the hopes of past generations, the joy of new life, and dreams for the future.

Whether realized immediately or gradually, the birth of a handicapped child changes the heart and soul of the entire family.

This realization always brings terrible pain to mothers and fathers as the image of their perfect child dies - must die - and is replaced by someone new and unknown.

We have asked ourselves, "Why? Why our child?" and, answered or not, found no solace. It was only when we could ask "what now?" that the healing began. The healing, though, left a tender spot.

Because our children were born when they were, and knowledge being the transient thing that it is, some families accepted recommendations of social workers and doctors. They gave the care of their children to others, to those they hoped could make life a little better.

Many of us worked hard to raise our children on our own. Resources were scarce. Useful information rare. For whatever reason, there came a point when we had no more energy. We had nothing more to give that could help. Some of us placed our children in foster homes and group homes. But ultimately, we turned to the State Hospitals (now known as Regional Treatment Centers).

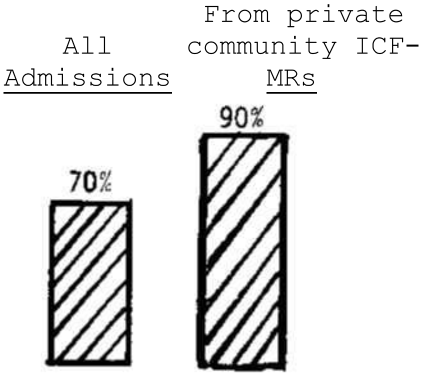
It was then that many of us were forced to give up four guardianship right's to get the services that our children needed.

Please remember the tender spot.

Some families could not bear the pain of those early years and never saw their child again. Do we not each cope differently?

We did not abandon our children. Our love for them has never died.

5. According to the 12/86 Court Monitor's Report, 70% of the new admissions to RTC's were behavior-related. Admissions from the community ICF/ MR's for reasons of behavior accounted for 90% of the admits. The definition of "for reasons of behavior is very broad and may include those who were aggressive, self-abusive, non-compliant and so on.



Behavior related admissions to RTCs by previous location.

6. Regarding the severity of behavior problems, one study (Harder, Kalachnik, Jensen & Feltz, 1987) estimates that 20% of the individuals discharged to community facilities in Minnesota were readmitted to the discharging Treatment Centers. These were persons who were aggressive to others or destroyed property in the community.

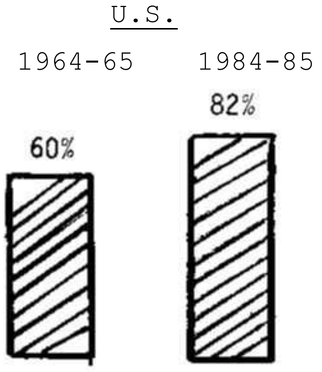
Many Service Providers are Needed

These observations and reports are a testament to the amount of staffing required and to the skills needed to bring about durable change in performance. This data suggests that is is a role to be played by many service providers. No one agency is best suited to a given task, though some have had to learn to meet the varied needs of their clients under trying circumstances. To say that "every handicapped person living in an institution has a twin in the community" assumes that all individual and family circumstances are identical, that there are not unique and important differences between people. It is simply another reflection by a "professional in the field" that only promotes guilt, pain, and suffering. It is as misleading and inaccurate as implying that simply being in a family home in a neighborhood is the sine quo non of integration and normalization.

National Trends

There are also some important National trends of which we need to be mindful (Scheerenberger, 1985)

- Of the 79,511 citizens living in the nation's residential settings, 82% are adults who are either profoundly or severely retarded.
- In the period between 1981 and 1985, the average number of persons over the age of 22 increased from 78% to 83%, and the number of individuals who were either profoundly or severely retarded increased from 80% to 82%.



Percentage of profoundly and severely retarded persons in residential

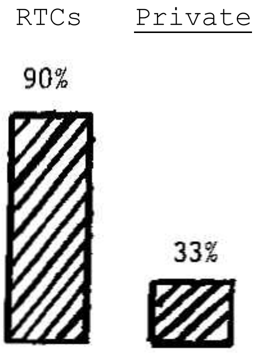
I. The Role of Public and Private Sectors: a balanced delivery" system.

The number of retarded citizens living in public residential facilities throughout the country between 1970 and 1985 has fallen from 189,000 to 105,000.

Minnesota exceeded the national pace (44%) by achieving a 57% reduction in the number of citizens living in the State's Region Treatment Centers. As of July, 1986, the population was 1845 (Court Monitor's Report, 12/86).

How long can we continue this pace? What does this mean for our State-operated programs? More importantly, is there a role for the public sector in the service delivery system? The Congress of Advocates for the Retarded, Inc. believes that the following facts need to be considered by our decision makers:

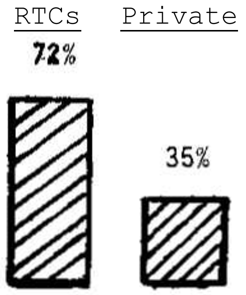
1. In 1982, 90% of our State's mentally retarded who lived in the State's RTC's were either profoundly and severely retarded. The percentage of profoundly and severely retarded persons living in Minnesota's community facilities during this time was 33%.



Persons with severe and profound mental retardation by RTC and private facilities. (1982)

2. A review of a number of documents, though not more recent than 1982, suggests that there are considerable differences between persons receiving services from Minnesota RTC's and community service providers, (community provoders include ICF/MR's, group homes, SLA's, SIL's, foster homes, and so on.)

3. We observe that, in 1982, 35% of individuals living in Minnesota's community facilities were dependent on others for their basic self-help skills. In the RTC's, 72% were dependent. This same pattern exists for skill areas such as toileting, eating, dressing, and grooming in more or less the same proportion.



Percentage of individuals who are dependent on others for self help.

4. Nationally, 32.8% of the new admissions to public residential facilities come from homes of parents or relatives. Indeed, 43% of the new admissions come from less restrictive settings. The apparent implication is that the community does not yet have the services required to meet the needs of the individuals for whom placements are sought.

Advocates agree. . .

The Congress of Advocates for the Mentally Retarded, Inc. agree with Pat Cook (Homeward Bound President) that "while community integration is a noble goal to strive toward, some human limitations and needs must be challenged. For persons with multiple handicaps and severe behavior problems, it often makes more sense to bring the world to them in a controlled, non-threatening manner."

One should not argue that our system has not worked. In every instance where one of our children has established a new life in the community, there has been a team of caring and dedicated individuals from Regional Treatment Centers who helped prepare the way.

Note: "Zero-reject" means that a program or county has adopted a position that no one, regardless of the extent of their problems, will be rejected or removed from the program. If a person fails in a program, our attitude must be "its not the fault of the person, it is the fault of the program. The program needs to be changed."

II. Input from families - does our opinion make a difference.

In these particular times the emphasis is on deinstitutionalization at all costs. The publicity in this area suggests that "the community" is the ultimate place for all handicapped people to live, work and play.

Surveys that have been done across the country and even those done within the State of Minnesota have not been considered.

All of these surveys document that a vast majority of family members are opposed to community placement and would prefer that their child remain in the Regional Treatment Center. These surveys document that the attitudes are based on concerns about services and needs of the individuals.

Since the majority of the family members are opposed to community placement, it raises the issue of exactly what rights parents have concerning their child.

The rights of the parents under Public Law 94-142 is impressive. The parents have the final say on their child's educational program. The schools can do nothing without their expressed consent.

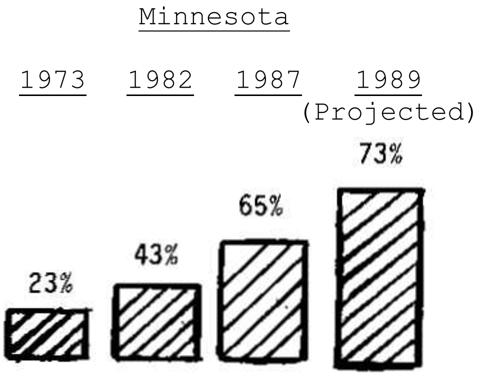
The rights of parents with a child in a Regional Treatment Center are considerably more obscure. Years ago it was recommended that parents place their children under State guardianship to protect the children when the parents died.

The philosophy that parental involvement was essential even though a child has been placed under State guardianship is supported by the actions of the RTCs. Parents are requested to attend individual program planning meetings, they are asked to sign consent for aversive behavior management programs and are asked to sign for the approval to use behavior altering drugs.

The Department of Human Services' actions over the last decade have also supported the philosophy that parental consent was required. Parents were asked to sign consent forms and the Department of Human Services would sign only if the parents or relative could not be found.

- More importantly, the percent of profoundly and severely retarded persons in the nation's facilities increased from 60% in 1964-1965 to 82% in 1984-1985.

- For Minnesota, in 1973, 23% of the individuals living in Regional Treatment Centers had a dependency for reasons of behavior. By 1982 the percentage increased to 43%. At the present rate of growth, nearly 65% of the population will exhibit either self-injurious or assaultive behaviors by the end of 1987. By 1989, the percentage will have increased to 73%. (Policy Analysis Series, No. 6, Jan., 1985)



Changes in RTC population by severe behavior problems.

We can conclude from this data and these National trends that community facilities are apparently serving less severely involved individuals than are the State's RTCs, This is partly the result of past policies. which have used RTC's as placements of last resort and the fact that the majority of our counties and community programs in the State of Minnesota have not adopted "zero reject" philosophies.

There is considerable variability in human capability, that a very small percentage of people are so incapable as to be classified as Category I individuals, and that long term care in RTCs is an entirely appropriate way of meeting their needs. Surveys show that parents consistently agree that there is a critical need for such long term care.

It is reasonable to assume that Regional Treatment Centers can have and should have a long term role in serving Minnesota's handicapped citizens.

However, the issue of who controls services was clarified and changed with the implementation of Rule 185, This gives the county social worker responsibility for determining needs, searching out service providers and approving services for those individuals that are under State guardianship (a majority of the RTC's population).

Today, the county social workers are caught in a "Catch 22." They are being asked to both provide services for the clients and indicate as guardian that they agree with the services that are being provided.

Recent informational bulletins sent to the counties by the Department of Human Services have attempted to correct this glaring conflict of interest. The bulletins state that a county social worker can not serve as both county case manager and guardian for a specific client. This requirement, however, means that the already overloaded county social workers (who have case loads of 100-200 clients) must find another county worker to act as the guardian for each of their clients.

Rule 185 - a problem

The Congress of Advocates for the Retarded, Inc. view the implementation of Rule 185 as problematic.

- Parents and families of clients have suddenly been eliminated from the picture.
- There are a number of counties who are refusing to sign the consent forms.
- The "other person" to be identified as the guardian within the county system has not been accomplished.
- The only recourse available to parents who object to decisions made for their children is to go to court,

III. Case Management: Adequate follow-and assurance or quality services.

Current State policy requires county case managers to oversee the delivery of services. Welsch vs Gardebring requires that mentally retarded persons discharged from State facilities be placed in community programs which meet their individual needs. However, the Consent Decree does not establish a clear standard for evaluating the appropriateness of community residential or developmental programs. The development of a clear standard has emerged as a major point of conflict and contributes to a service delivery system from a consumer viewpoint that is fragmented and unreliable. For example, the Office of the Legislative Auditor, February 1986, reported that "allegations of noncompliance regarding appropriateness of community placement affected at least 35 individuals residing in 17 group homes.

Furthermore, the Court Monitor has pointed out that the staff of RTC facilities have an obligation to state their professional objections to a specific community placement. This is in conflict with the pressure placed on RTC staff by DHS to demit residents according to arbitrary schedules drawn up by both DHS and the Court Monitor.

We believe that:

1. Without competent and effective case managers with reasonable case loads, appropriate services are often unobtainable, inadequate, and inconsistent.

2. DHS needs to examine, plan and establish with the counties more realistic levels of expectations for effective case management systems.

3. Numerous small settings scattered all over the counties are extremely difficult to monitor for quality care.

On the other hand, it has been our experience that RTCs undergo numerous checks and balances to ensure that the services delivered are of the highest quality possible. In addition to the issues of required compliance (Rules 3 and 34, licensure requirements. Department of Health, Fire Marshall's office, Welsch Consent Decree requirements, and ICF/MR regulations), some RTCs participants in further voluntary reviews of service (ACMRDD, CARF, and JCAH).

Within each facility, policies dictate the length and depth of review for each individual program. Families and relatives of residents in RTCs are allowed to provide input into program reviews through participation in the Interdisciplinary Team process, Regional Advisory Committees, and other parent organizational activities. There is a lack of evidence that such intensive processes are practiced in all community facilities.

We believe that the more involved families are in the monitoring of services, the more confident and secure they will feel about the quality of case management services in general.

Additionally, distinct conflict of interest is now inherent in Rule 185 by making the case manager responsible for both judging the adequace of services, finding the least costly services, and supervising the financing of these services. This will ultimately lead to choices by case managers, because of the pressure to minimize costs, that will deny persons with mental retardation suitable services.

The Congress of Advocate for the Retarded, Inc. has seen no plan from DHS, nor the necessary budget support to suggest that the problems with case management will be solved in the immediate future. We believe that case managers should address three issues:

1. Is the person better off today than they were in the past?

2. Would you want your son or daughter living and participating in a program like this?

3. How do families feel about the quality of services provided to their relative?

IV. Choices and alternatives.

It has been indicated by some advocates that "mental retardation has a long history of failure and short history of success (Foster, 1974)." For the past decade, professional and public concern about the provision of appropriate residential care for persons with mental retardation has increased dramatically (Landsman-Dwyer & Sluzbacher, 1981). For better or worse, we live in an era where the predominant thrust of public policy concerning residential alternatives for persons with mental retardation has been toward the provision of small community-based facilities with decreased emphasis and reliance on the use of large state-operated programs. The widespread acceptance of the "normalization principle" in this country has provided great impetus for the current bias for small community-based residential settings.

Many advocates will argue that the quality of care for persons with mental retardation is far superior in smaller settings compared to large state-operated programs. However, many parents and relatives having sons or daughters in state-operated facilities would disagree. Tom Gardner (a parent with the Homeward Bound program) has stated that "<u>the myopic theory that small is always best and one size fits all is totally unacceptable.</u>"

The "long history of failure" that Foster refers to is directly related to the lack of choices and options that parents initially faced when confronted with the problems of their handicapped children. There were no options or alternatives available for them other than placement in state schools and hospitals at that time.

In the rush to join the bandwagon of "deinstitutionalization" and "normalization," it appears to many of us that we are about to commit the same grave error proponents of previous movements made in the past; i.e., prescribing one alternative to serve a highly diverse population and limiting both options and choices along the way.

McDonnell, Wilcox and Boles (1986) have stated that "existing community service programs are characterized by low wages, limited access to community environments, isolation from non-handicapped peers, and little movement to less restrictive service programs." The absence of effective community service programs for adults has created a cruel irony for individuals who have stayed in their own communities to attend school. Instead of having access to service programs that will maximize the benefits of their educational entitlement, most graduates will encounter the same limited range of adult service programs that were available to their peers a decade earlier who typically received no education or training at all.

Parents having relatives in State-operated facilities where a majority of these services are provided on a comprehensive basis cannot help wonder why so much emphasis is placed on dismantling programs and moving individuals into community programs that have long waiting lists of adults who still live at home.

The Minnesota Chapter of the Congress of Advocates for the Retarded, Inc. will not support a system that continues to deny, delay, and dismantle services when the needs of so many disabled citizens are at stake.

"if its not broke, don't fix it"

V. <u>Ensuring adequate staffing/funding</u>.

Quality programs for individuals with mental retardation or other developmental disabilities demand sufficient staff ratios and adequate training to ensure health and safety as well as appropriate habilitation and training.

The Welsch Consent Decree ratios established in 1980 no longer provide adequate staffing in RTCs. It is true that Welsch staffing requirements call for overall ratios which did not take into consideration the dramatic shift in the concentration of individuals with severe, multiple handicapping conditions, and severe behavior problems. Higher staff to client ratios may actually be needed because of the increased emphasis on accountability, documentation, and adherence to regulations.

Staff ratios in community-based programs exceed the staff ratios set by the Welsch Consent Decree. However, it should also be noted that community based staff are compensated at a rate approximately 30%-40% lower than staff from RTCs, resulting in higher job dissatisfaction and higher job turnover. The overall lack of continuity in many of the community programs may be traced to this staff turnover problem and lower wages.

One of the assumptions that parents have heard for years is that as individuals left RTCs, staffing levels would remain the same, consequently improving staff to resident ratios. This has not happened since 157 staff positions were reduced from the Legislature compliment in July of 1986. An additional 297 positions must be deleted by June 30, 1987. DHS's proposed biennium budget called for an additional 349 positions in FY 88 and FY 89. Following the Governor's budget proposal to the Legislature, we were disheartened to learn that the Department of Finance has recommended reductions of somewhat between 500 and 600 positions.

At the same time, adequate staffing must be accompanied by adequate funding.

VI. Controlling the pace of deinstitutionalization.

Perhaps, one of the more important findings touched on in the February, 1986, Legislative Auditor's Report concerning Deinstitutionalization of Mentally Retarded People was the following statement:

> *"The Department will have difficulty achieving its accelerated schedule of reductions."*

For many years, parents and consumers have heard that these reductions from State facilities were necessary to meet Consent Decree compliance. Part III of the Consent Decree does require a 30% reduction. Paragraph 12 of the Consent Decree stipulated that by July 1, 1987, the population of mentally retarded persons in State facilities should not exceed 1850 persons. The Sixth Report to Federal Court submitted by Richard Coehn (December, 1986) indicated that the population in State facilities for persons with mental retardation was at 1856 persons as of July 1, 1986. DHS's actual intent was to reduce the population of mentally retarded persons beyond the Consent Decree requirements thereby accelerating the rate of placements. This effort is being undertaken in spite of the fact that the Consent Decree objectives have been met a year earlier than anticipated.

DHS's primary strategy for achieving this accelerated reduction involved an expansion of the State's program of home and community-based services funded under the Medical Assistance Waiver. DHS needed to accelerate its reductions out of State facilities in order to fulfill the assurance it made when it secured Federal approval for the Waiver. The pressure to achieve these goals has created major problems for individuals and counties

VII. Expanded uses of Regional Treatment centers

RTCs, if they are not viewed in a negative fashion, can be looked at as tremendous regional resource and training centers for multicounty areas across the State of Minnesota. There are a number of very important functions that RTCs can perform with the skilled concentration of expertise that exists in all facilities. Some of these functions that we have identified include the following:

1. RTCs have historically performed a "backup function" to provide services for more difficult residents who need structured program settings. This primary responsibility should be maintained in future planning efforts.

2. RTCs should serve as expanded respite care centers providing emergency housing, evaluation and crisis intervention services for persons and families who need these services when other options are not available to them.

3. RTCs should provide expanded outreach services to the larger community, making specialized staff and equipment available on a Region-wide basis.

4. RTCs should establish Regional Training Centers to work closely with local community colleges and AVTI programs to develop pre-service and other health care inservice programs.

5. RTCs should establish and expand State-operated group homes to not only provide services in the "county of meaningful ties," but to expand available choices to families and relatives who might be interested in this type of a program.

The Minnesota Chapter of the Congress of Advocates for the Retarded, Inc. believes that the purpose of State-operated group homes is:

1. To provide persons with mental retardation who are in RTCs and others who may otherwise need the services of a RTC with individually tailored services in their home communities;

2. To provide services that are integrated within local communities;

3. To expand service building capacity in local communities;

4. To utilize RTC employees to develop and deliver services;

5. To strengthen community programs and fill gaps in the array of services; and

6. To assure a mix of public and private providers that will facilitate quality care.

VIII. Need for flexible long range plan

After reviewing the State of Minnesota's Development Disabilities Three Year Plan developed by the Governor's Planning Council on Developmental Disabilities, one can only conclude that we do not have a comprehensive long-range plan for mental retardation services in this State.

who feel their "arms have been twisted." For the most part, their concerns over this rapid movement have largely been ignored. Numbers and dollars have become more important concerns than the effects of this movement on families and residents.

Controlling the pace of deinstitutionalization is difficult to plan for because most planning efforts occur in two year segments and are affected by national and state "whims" which can occur at any time. It appears to us that either trying to maintain the current pace or making efforts to accelerate that pace is not only risky but also dangerous. The remaining RTC residents are the most difficult persons to be served with very complex medical and behavioral problems.

Since July, 1983, not only has there been a moratorium on the develop-ment of new ICF/MR beds, there has also been increased emphasis by DHS on decertifying existing beds and "down-sizing" larger ICF/MRs. When the Waiver was initially approved in 1983, it was supposed to provide alternatives, but there have been insufficient slots and the allowable average per diem is too low to meet the needs of the more difficult to serve individuals. Moreover, there is a risk involved should the new placements not work out. Residents can not be returned to their previous placements if their beds have been decertified. There have been many situations where individuals have been held in accute care hospital settings unqualified to meet their needs. Finally, there is a risk even if the placements do work. Many people are aware that the current Waiver was limited to three years. With Medicaid under attack, who will pay the costs if the funding is cut back or ended for this needed level of service?

With resources limited for persons with mental retardation, this emphasis upon deinstitutionalization either out of State-operated RTCs or larger ICF/MRs gives priority to Regional Center discharges at the expense of handicapped persons who live in the community and need these same services. It focuses on numbers and generates unbelievable pressure within the system, accelerating the rate of change.

The Minnesota Chapter of the Congress of Advocates for the Retarded, Inc. believe very strongly in the following points:

1. The pace of deinstitutionalization must be carefully controlled and related to not only having resources available but also directly to requests from families and relatives supportive of impending placements. County case managers should be talking with families about placements before deciding by fiat that someone should be placed regardless of concerns about the placement and availability of community programs.

2. The DHS will have difficulty achieving its accelerated schedule of reductions because of the difficulty level of residents left in RTCs, and because of the unmet needs that exist throughout numerous counties in Minnesota.

3. Families as taxpayers, as parents, and as responsible citizens should have a more definitive voice in the long-range planning that occurs regarding the future of their children.

The Minnesota Chapter of the Congress of Advocates for the Retarded, Inc. makes the following recommendations:

1. DHS should establish a viable long- range plan for State-operated RTC's.
2. This planning document should address the differences between "State Hospitals" and "Regional Treatment Centers."
3. Individual members from the Congress of Advocates for the Retarded, Inc. should be members of this planning team.
4. Draft documents for long-range and options should be circulated to all RTCs for Advisory Committee and parent input.
5. The long-range plan itself, before it is finalized, should be subject to public hearings.

ARC MINNESOTA DOES NOT REPRESENT OUR VIEWPOINT ON THESE NATTERS

IX. Mental Health Initiative

The Minnesota Chapter of the Congress of Advocates for the Retarded, Inc. wishes to go on record that -

1. We support adequate funding for the mental health initiative to improve the quality of mental health services in the State of Minnesota;
2. We will never support efforts or attempts to fund the mental health initiative by reducing the funding for badly needed services for persons with mental retardation;
3. We do support responsible and responsive leadership to see that our mental health and mental retardation programs are adequately funded to help improve the quality of life for our most disabled citizens;
4. We do support policies that avoid the disastrous effects that "dumping" has had on our mentally ill populations.

"LET'S NOT ROB PETER TO PAY PAUL"

SUMMARY PAGE

The Minnesota Chapter of the Congress of Advocates for the Retarded, Inc. have included within this position paper the following major points that we would like to highlight for your attention.

1. We support a system of choice that allows parents and relatives to utilize services in both the public and private sector.
2. No single mode of service is best for all people.
3. RTCs should have a long-term role in providing services.
4. Limitations regarding the use of community services needs to be acknowledged in planning efforts.
5. Parents with children in RTCs have not been allowed the opportunity to discuss their views on the State's deinstitutionalization policy.
6. A majority of families and relatives are very pleased with the services provided by the RTCs.
7. Many parents and relatives currently feel that their rights are being usurped and being taken away completely by the county case manager per Rule 185.
8. Case management is a fragmented system that needs to be strengthened.
9. Families and relatives should have input and involvement in the measurement of quality of services provided by both the RTCs and community programs.
10. The prescription of one alternative to serve a highly diverse population limits options and choices.
11. Adequate staffing and funding is needed to ensure that the health, safety, and habilitative needs of persons with mental retardation are met.
12. Deinstitutionalization should not occur in an overly rapid fashion which results in the "dumping of residents."
13. Families should have a more definitive voice in the long-range planning regarding the future of their children.
14. Individuals are more important than numbers, quotas, slots, or statistics.
15. DHS policy objectives should be two-fold: least restrictive and most appropriate.
16. DHS needs to establish a viable long-range plan for RTCs with involvement from the Congress of Advocates for the Retarded, Inc.
17. ARC Minnesota and Legal Advocacy for the Developmentally Disabled does not speak for the Congress of Advocates for the Retarded, Inc.
18. DHS should support the establishment and development of additional State-operated group homes to promote greater choices, alternatives and quality assurance initiatives.
19. RTCs should be used as regional resource and training centers.
20. Let's not rob Peter to pay Paul.

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