GOOD MORNING, MR. CHAIRMAN AND MEMBERS OF THE COMMITTEE. MY NAME IS COLLEEN WIECK, VICE PRESIDENT OF THE NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES COUNCILS AND CHAIR OF THE NADDC PUBLIC POLICY COMMITTEE. I HAVE ALSO BEEN THE EXECUTIVE DIRECTOR OF THE MINNESOTA DEVELOPMENTAL DISABILITIES COUNCIL FOR THE PAST 5½ YEARS. ON BEHALF OF ALL STATE DEVELOPMENTAL DISABILITIES COUNCILS, WE APPRECIATE THE OPPORTUNITY TO TESTIFY ON NEEDED CHANGES IN THE MEDICAID PROGRAM.

DEVELOPMENTAL DISABILITIES COUNCILS ARE IN A PARTICULARLY STRATEGIC POSITION TO UNDERSTAND THE IMPACT OF MEDICAID ON THE LIVES OF PEOPLE WITH DEVELOPMENTAL DISABILITIES. OUR COUNCILS ARE COMPOSED OF BOTH CONSUMERS OF SERVICES AND GOVERNMENT OFFICIALS RESPONSIBLE FOR PROVIDING SERVICES. WE UNDERSTAND BOTH THE PROBLEMS AND THE POTENTIAL OF MEDICAID.

MY TESTIMONY IS DIVIDED INTO FOUR MAJOR SECTIONS CRITICAL TO ANALYZING THE IMPACT OF MEDICAID ON PEOPLE WITH DEVELOPMENTAL DISABILITIES. THE FIRST TWO SECTIONS POINT OUT THE PROBLEMS CREATED BY THE CURRENT MEDICAID PROGRAM WITH RESPECT TO THE RELATIONSHIP OF COST TO OUTCOMES AND THE IMPACT ON FAMILIES.

THE THIRD SECTION FOCUSES ON THE INEVITABLE AND TOUGH CHOICES THAT FEDERAL AND STATE OFFICIALS FACE IF WE ARE SERIOUS ABOUT RESTRUCTURING AND REALLOCATION. THE FOURTH SECTION ADDRESSES PRINCIPLES AND SOLUTIONS TO FUND WHAT IS RIGHT AND EFFECTIVE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES.

FIRST, BILLIONS OF DOLLARS ARE SPENT ON MEDICAID SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, BUT WHAT ARE THE OUTCOMES? MEDICAID MAY FOSTER "RETARDING ENVIRONMENTS" AND "INACTIVE TREATMENT."

THERE IS NO DOUBT THAT MEDICAID HAS GREATLY IMPROVED SERVICES AND ENRICHED STAFFING FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES. HOWEVER, THERE ARE SERIOUS DEFICIENCIES THAT MORE MONEY CANNOT FIX.

WHETHER THE SOURCE OF INFORMATION IS UNIVERSITY RESEARCH, STATE LICENSING AND CERTIFICATION REPORTS, HCFA LOOK BEHIND AUDITS, ACMRDD REPORTS, OR LOWELL WEICKER'S REPORT ON CONDITIONS IN INSTITUTIONS AND COMMUNITY FACILITIES, THERE IS A SINGLE THREAD RUNNING THROUGH ALL REPORTS--AT THE INDIVIDUAL LEVEL--WHAT DOES THE PERSON <u>NEED</u> AND WHAT IS THE PERSON <u>RECEIVING</u>. DOES MEDICAID FUND DEPENDENCY RATHER THAN INDEPENDENCE, DOES MEDICAID FOSTER INACTIVITY RATHER THAN PRODUCTIVITY, DOES MEDICAID KEEP PEOPLE SEGREGATED RATHER THAN ENCOURAGE INTEGRATION INTO COMMUNITY LIFE? RESTRUCTURING IS NECESSARY TO ADDRESS THESE CONSEQUENCES.

SECOND, MEDICAID IS A POWERFUL INCENTIVE FOR OUT-OF-HOME PLACEMENTS.

FOR THOSE FAMILIES WHO HAVE KEPT THEIR CHILDREN WITH DEVELOPMENTAL DISABILITIES AT HOME, THEY QUICKLY REALIZE THAT GOVERNMENT PROVIDES SERVICES IF THE CHILD OR ADULT LEAVES HOME.

SERVICES TO SUPPORT FAMILIES AND CHILDREN AT HOME FINISH LAST WHEN COMPARED TO FUNDING FOR INSTITUTIONS AND GROUP HOMES. OVER HALF THE STATES HAVE BEGUN FAMILY SUPPORT PROGRAMS; BUT WHILE STATES ARE TRYING TO SUPPORT FAMILIES, MEDICAID FUNDS SERVICES TO SUPPLANT FAMILIES.

WE DO HAVE THE MEDICAID HOME AND COMMUNITY-BASED WAIVER PROGRAM WHICH HAS THE FLEXIBILITY; HOWEVER, IT IS A VERY LIMITED PROGRAM.

THIRD, RESTRUCTURING MEDICAID MEANS FACING TOUGH ISSUES, MAKING INEVITABLE CHOICES, AND ENDURING POLITICAL HEAT.

LARGE MEDICAID FUNDED RESIDENTIAL SERVICES ARE BEING DOWNSIZED. CONTINUED REDUCTIONS ARE INEVITABLE. AS A RESULT, . . . WE HAVE CRITICAL ISSUES TO FACE WHEN WE TALK ABOUT RESTRUCTURING AND THAT MEANS:

- EMPLOYEE DISLOCATION;
- WHAT TO DO WITH BUILDING AND LAND;
- WHAT TO DO ABOUT ECONOMIC IMPACT ON LOCAL COMMUNITIES;
- HOW TO STRUCTURE A PUBLIC PROCESS; AND
- WHAT TO DO ABOUT TRANSFERRING RESIDENTS.

IN MINNESOTA, WE HAVE UNDERTAKEN A STUDY OF THESE ISSUES AND HAVE PRODUCED EIGHT POLICY PAPERS THAT CAN BE USED BY OTHER STATES IN ADDRESSING THESE PROBLEMS.

WHATEVER CHANGES ARE MADE TO MEDICAID, THERE SHOULD BE ADMINISTRATIVE LEADERSHIP TO ASSURE INVOLVEMENT OF FAMILIES, ADVOCATES, EMPLOYEES, AND COMMUNITY LEADERS.

WE HAVE TO MOVE AWAY FROM PERPETUATING BRICKS AND MORTAR "TO EMPOWERING INDIVIDUALS AND FAMILIES."

FOURTH AND FINALLY, RESTRUCTURING MEDICAID MEANS CATCHING NEW WAVES, FUNDING WHAT IS NEEDED AND WHAT IS POSSIBLE.

INNOVATION IS OCCURRING THROUGHOUT THE UNITED STATES. WE ARE BEGINNING TO TALK ABOUT REAL HOMES, REAL JOBS, REAL FRIENDS, AND THE REAL COMMUNITY, NOT "PHONEY CREATIONS OF SERVICE SYSTEMS" WHICH PERPETUATE CLIENTHOOD RATHER THAN CITIZENSHIP.

INCLUDED IN MY TESTIMONY ARE 10 FEATURES OF MEDICAID FUNDED SERVICES AND 10 CHARACTERISTICS OF A REFORMED SYSTEM.

TESTIMONY OF:

Colleen Wieck, Ph.D.
Executive Director
Minnesota Governor's Planning Council
on Developmental Disabilities
201 Capitol Square Building
550 Cedar Street
St. Paul, Minnesota 55101

TO:

Senator John Chafee
and the
Community and Family Living
Amendments Forum
Chicago, Illinois

April 12, 1986

Senator Chafee and Forum participants.

The Minnesota Governor's Planning Council on Developmental Disabilities supports the Community and Family Living Amendments and has supported the bill since 1984. We provided written testimony to your Senate hearing which was held on August 13, 1984, in Minneapolis that outlined the values, issues, and philosophical reasons for our support. We stated at that time:

1. CFLA supported a consumer driven system rather than a provider driven system.

2. CFLA would help meet demands for service through a range of alternative living arrangements.

3. CFLA would emphasize meeting the needs of individual residents in small, homelike residential programs.

4. CFLA would provide less costly alternatives to out-of-home placements.

5. CFLA would emphasize and strengthen support services such as day programs and case management.

6. CFLA defines the target population in comparable terms with our state statutes, but more attention is needed for emotionally disturbed children and people with mental illness.

Rather than repeating our original testimony, the Council directed me to testify about the results of a nine-month study of our state hospital system. We are interested in discussing the broad range of issues that each state must face in downsizing residential facilities.

During the 1984 Legislative Session, the D.D. Council of the State Planning Agency was given lead responsibility to conduct a study and propose a plan for state hospitals. There were four events that prompted the legislation: (1) the sudden closure of Rochester State Hospital, (2) the Title XIX Home and Community Based Waiver which called for additional reductions in the mental retardation units, (3) the Welsch v. Levine Consent Decree, and (4) the December 1983 proposed reorganization of the state hospital system by the Department of Human Services.

We completed eight separate reports which you have in front of you. Each of these reports answers specific questions

posed by the legislation. In addition to these reports, we published this 40-page graphically illustrated report giving "highlights" of the reports.

An interagency board was established and consisted of 11 state agency commissioners. The interagency board entitled, the Institutional Care and Economic Impact Planning Board, met six times to carry out its mission. This board approved all reports and recommendations that were presented to the Legislature.

Let me emphasize that Minnesota has plenty of plans, and some would argue that our state hospital system is over-studied. The problems with planning is that when major stakeholders are not involved, the planning is meaningless. Second, the Legislature can act without planning or can require planning and then not act. The study that we conducted involved all stakeholders and did result in legislative action.

The first priority in planning must be the individuals who are served; however, other issues need attention such as economic impact, employee displacement, and alternative use of buildings. My testimony will describe how we organized these studies and the conclusions we reached.

PAPER NO. 1: MINNESOTA STATE HOSPITAL FACILITIES AND ALTERNATIVE USE (BUILDINGS)

The major focus of this study was an analysis of the general condition of the buildings and potential alternative uses of those buildings.

We examined several variables including the years the buildings were built, property size, building square footage, physical condition, plumbing condition, and electrical condition of the buildings.

There are many buildings in the state hospital system which are unused and in poor repair. Many of these buildings continue to be heated because they have not been declared surplus property. There are tables on the disposition of surplus property from 1983-1984 in this report, and our analysis shows that the state does not excel at disposing surplus property.

Even though the projection for services for mentally ill people and chemically dependent people remains constant for the next biennium, the projected decline of people who are developmentally disabled will reduce the current need for building space.

There has been considerable experience across the United States concerning the conversion and disposal of state

hospital properties. We conducted a national survey of states with 43 of 50 states reponding.

Generally speaking, state agencies report that they do not save money by using state hospitals for other government uses rather than renting or building other facilities. This is due in large part to the condition and age of the buildings, energy costs, and renovation costs.

Of the 31 institutions reported closed nationwide, none have been purchased by private industry. Over half have been converted to other types of institutions, e.g., corrections, Veteran's, geriatric apartments, college, and religious organization.

Recommendations:

1. We recommended a systemwide capital improvement planning process that recognizes long-term space requirements and the condition of the buildings.

2. We recommended that unused buildings in poor condition should be declared surplus and demolished if necessary.

3. We recommended an aggressive, coordinated marketing strategy should be undertaken for all potential alternative uses of state hospitals. Specific use decisions will require the active involvement of state, county, and local agencies, and affected communities. The uses should not conflict with established state policy and should be compatible with the purpose of state hospitals.

4. We supported proposed changes in state law easing constraints on the sale of state property to the private sector.

PAPER NO. 2: MINNESOTA STATE HOSPITAL ENERGY USE AND COST

Energy consumption in buildings is affected by many factors including original construction features, efficiency of heating plant, severity of weather and type of heating fuel used. Meaningful comparison of energy use at the eight state hospitals is difficult.

The Legislature directed us to analyze the energy efficiency of all state hospital buildings. The analysis was accomplished in five different ways:

1. Energy use by resident/patient;

2. Energy cost per resident/patient (FY '83 in 1982 dollars);
3. Energy use by square foot/degree day/MMBTU;
4. Energy use and cost by square foot of building space (FY '83); and
5. Energy cost as a percentage of operating cost.

Recommendations:

We recommended that energy conservation measures continue to be taken:

1. Utilization of shared savings contracts;
2. Use of alternative fuels;
3. Purchase of electricity from wholesalers;
4. Separate metering of leased or rented buildings to the tenants;
5. Surplus buildings to be identified for demolition to eliminate heating costs; and
6. Energy improvements such as a summer boiler.

PAPER NO. 3: A PROFILE OF MINNESOTA STATE HOSPITAL EMPLOYEES

The legislation authorizing the study was very concerned about the effects on the employees should a state hospital close. The legislation sought specific information about the employees: What is the projected displacement of state hospital employees because of deinstitutionalization, and what is the extent to which displacement can be mitigated through attrition, retirement, retraining, and transfer?

There are over 5,900 people, including part-time and intermittent employees working at our eight state hospitals.

1. 64 percent of all employees are female; the majority are covered by the Non-Professional Health Care Unit, which is the largest bargaining unit, and this group of employees earn an average wage of $8.51 per hour.

2. The average length of service for all employees is 8.15 years.

3. The separation rate for all employees (all forms of termination: death, voluntary, and involuntary retirements) varied greatly in the state hospital system. The total number of separations for FY '84 was 820.

4. Under the Rule of 85 (if a person's age and years of experience equals 85), 369 employees are currently eligible for retirement. If

the Rule of 85 were extended, 742 additional employees would be eligible within five years.

The State Planning Agency conducted a survey of state hospital employees to determine future career choices. There were 26 questions, and 3,154 employees responded to the questionnaire.

Here are some results:

Question: "If this state hospital were to close within the next five (5) years, or if patient/resident reductions were to result in staff reductions, and if I were offered a transfer to another state hospital for a similar position, I would most likely . . .." The hypothetical question was followed by a set of four (4) choices:

1. Maintain my current residence, refuse the transfer, and seek other employment elsewhere. 34%

2. Refuse the transfer, seek other employment outside the area, and change my address accordingly. 12%

3. Accept the transfer and move to the area offered. 24%

4. Accept the transfer but would attempt to maintain my current residence and commute if at all possible. 27%

5. Unknown. 2%

Question: "If this state hsopital were to close within the next five (5) years, or if patient/resident reductions were to result in staff reductions, and if I chose not to accept a transfer to another state hospital, my next career preference would be . . .."

1. Work for a state agency in the field of human services. 31%

2. Work for a state agency outside the field of human services.

3. Work in another public sector (city, county, federal) in the field of human services. 20%

4. Work in another public sector (city, county, federal) outside the field of human services.

5. Work in private industry in the field of human services. 12%

6. Work in private industry outside the field of human services.

7. Retire, if possible. 7%

8. Self-employment. 14%

9. Return to school. 5%

10. Unknown. 11%

Question: "Should you wish to continue in the human services field, what would be your most preferred work setting?" The choices on the questionnaire were:

1. State hospital. 54%

2. Privately operated community program (day or residential). 11%

3. State-operated community program (day or residential). 22%

4. County-operated community program (day or residential). 7%

5. Unknown. 6%

We also examined the question of portability of pensions. Pensions are portable in some cases but cannot be transferred when leaving public service.

Recommendations:

1. We recommended that any staff reductions resulting from declining state hospital populations should occur through natural attrition and retirement whenever possible.

2. The Department of Human Services and the Department of Employee Relations should develop a plan to facilitate the volutary transfer and retraining (i.e., retraining of workers transferring to mental illness units).

PAPER NO. 4: THE ECONOMIC IMPACT OF MINNESOTA STATE HOSPITALS

A large industry such as a state hospital contributes significantly to a community's economy. The smaller the community

and less diverse its commercial or industrial base, the greater the impact of any closure or downsizing. Economic impact is not only a function of where employees live and spend their money but also where they work in terms of commuting distance.

For purposes of the report, there are three economic impact areas. We used zip codes to define the areas:

1. Primary impact zone is wehre 50 percent of the employees live. (Zip codes closest to state hospital.)

2. The secondary impact zone is where 75% of the employees live (includes the primary impact zone).

3. The regional impact area is where at least 90 percent of the employees live and includes both primary and secondary zones.

4. This report has several sections:

   a. Direct Effect of Hospital Employment:

      — employment as a percentage of total area employment;
      — hospital payroll as a percentage of total area wage and salary income; and
      — estimates of unemployment by county.

   b. Indirect Employment Loss.

   c. State Hospital Purchases.

   d. Effect of Resident/Patient Spending.

   e. Effect of Visitor Spending.

5. Counties where most state hospital employees reside are:

a.	Rice	1,017
b.	Crow Wing	647
c.	Otter Tail	637
d.	Kandiyohi	605.

6. Alternative employment would be more difficult in an area of high unemployment. State hospital counties' unemployment rates as of July 1984 showed a high in Carlton County (Moose Lake) of 10.1 percent, 8.0 percent

in Crow Wing (Brainerd), and 7.9 percent in Otter Tail (Fergus Falls).

7. Salaries of state hospital employees may be the most significant factor in community economic impact. Of the total operating expenditures, $128,433,135, or 85.9 percent, are for personnel costs. The amounts ranged from $9,809,295 at Anoka State Hospital to $24,993,232 at Faribault.

8. Since the state of Minnesota has a centralized procurement system based in St. Paul, the local state hospital purchases as a percentage of local retail sales are small as shown by the tables on pages 20-26.

Recommendations:

We recommended that alternative economic development strategies can be developed but require a cooperative effort between state and local officials. Economic impact zones may be one way to handle this issue in the future.

PAPER NO. 5: PUBLIC OPINIONS ABOUT STATE HOSITALS

A significant part of the study of the state hospital system was the development of a public process which provided Minnesotans with an opportunity to express ideas and concerns regarding the future of state hospitals and the delivery of services to persons with mental illness, mental retardation, and chemical dependency.

This public process involved three major elements:

1. The convening of nine town meetings, one in each area of the state served by a state hospital and one in the Metro area. (Over 5,000 people attended. There were 362 witnesses, and 80 separate organizations were represented.)

2. Soliciting letters from the public and interested parties who would express their views. (Over 433 letter were received.)

a.	Pro state hospital	117
b.	Neutral	15
c.	Pro community-based facilities	121
d.	Opposed the waiver	49
e.	Against state-operated community facilities	131.

3. Receiving calls during a "toll-free call-in" day. A total of 202 calls; 174 favored state hospitals.

4. We also sent a "Dear Colleague" mailing once a month to 1,500 people giving results and announcing meetings.

The overwhelming message of the town meetings and phone calls was to keep the state hospitals open. The letters were split on this issue.

Here are the major themes that we heard at the town meetings:

Concerns about Patients and Residents:

- The special needs of residents should be the primary concern in planning the future of state hospitals.

- Persons most "difficult to place" because of severe behavioral, physical, medical, comunication, or multiple handicap problems are served by state hospitals.

- Residents and patients need quality care and a base of support--state hospitals are the only home they have, they should not be made "homeless" nor "shuffled about."

- The improvement of residents and patients has been documented. Individuals described the progress they have made. Some families prefer the state hospital placement.

- The fact that state hospitals are geographically dispersed makes it easier for families to visit. Closure is viewed as forcing families to travel longer distances.

- During the call-in day, several callers cited incidents and criticized both state hospitals and community services because of inadequate or inappropriate treatment.

- Family members requested greater involvement and respect from staff.

Views on Community Programs:

- Individuals have moved out of institutions and into the community. They have improved.

- Community programs (community mental health centers, case management, and community support programs) need more financial support.
- Community placement will occur, but it must be orderly.
- Community-based services are client-centered and provide integration.
- Residents have a right to live in the community. The state hospital is not the least restrictive environment.
- The state should phase out of operating any program. The state should use a "request for proposal" approach. The state cannot provide services and at the same time monitor itself.
- We need a state policy on deinstitutionalization.
- Do not stop community-based facility development because of employees and economic impact issues.
- Community services are not available in all parts of the state.
- Some community services experience high staff turnover. Staff aren't well trained. Community services are underfunded. Community programs do not provide a full range of therapy and health care services. Class action suits may be necessary to address inappropriate placements in the community.
- Community-based facilities do not accept all types of people.
- Community programs do not provide the same level of care as state hospitals.
- There is abuse in the community programs and overmedication in some.
- Community facilities are not prepared for the clients who are leaving state hospitals.
- County case management is understaffed.
- Some state hospital programs are smaller than larger group homes.

Quality of State Hospital Staff and Care:

- State hospital staff and the care provided were described as caring, helpful, dedicated, the best, concerned, enthusiastic, skilled, superior care, excellent care, warm, professional, and nationally recognized.

- Staff care about residents and provide a surrogate family relationship 24 hours per day.

- Staff are concerned about quality of care, continuity of care, standards, and a multidisciplinary approach.

- State hospital staff salaries are justified because the residents are the most difficult to serve. The salary levels in the community are low by comparison.

- Staff turnover rates are lower in state hospitals compared to community services.

Community Economic Impact on Hospital Closure

- The effect will be an economic chain reaction characterized by direct loss of hospital jobs, indirect loss of jobs because of slowed industrial growth, lowered gross community income, reduced retail sales, closed stores, fewer families, underutilized schools, increased taxes, higher utility costs, depressed housing market, and rising unemployment.

- Several attempts to estimate the magnitude of the economic impact were presented.

A summary of every town meeting is provided in this policy paper. A file of letters is also available and copies of transcripts from the meetings.

PAPER NO. 6: RESIDENTS/PATIENTS

Minnesota's state hospitals exist to serve people with mental illness, developmental disabilities, and chemical dependency. While there are many factors which will influence the future of state hospitals, a very important factor must be the individuals for whom they exist.

All eight state hospitals do not provide the same services. Cambridge and Faribault state hospital serve only persons with developmental disabilities; Anoka serves only persons with mental illness and/or chemical dependency.

The state hospital study also found:

1. In 1960, a peak of 16,355 residents/patients were served in the state hospital system.

2. In FY '84, the average daily population of the state hospitals was 4,006 people: 1,230 people who were mentally ill; 2,182 people who were developmentally disabled; and 594 people who were chemically dependent.

3. Patients who were mentally ill range from the severest forms of illness (9 percent) to the least severe symptoms (12 percent). Patients who experienced psychotic episodes, attempted suicide, and abused drugs comprised 26 percent of the state hospital population; and patients with poor social skills, little initiative, and difficulty controlling emotional control comprised 39 percent of the population. The remaining 13 percent have limited social interaction and self-care skills.

4. 90 percent of the residents in state hospitals were severely or profoundly mentally retarded.

5. Residents who were developmentally disabled were highly dependent in areas such as self-preservation (ability to egress a building on their own in case of an emergency), behavior problems, bathing, grooming, and dressing.

6. Patients with chemical dependency were typically young white males who were single, unemployed, had a high school degree or less, were alcohol dependent, and were indigent.

Recommendations:

The study of "Patients and Residents in Minnesota State Hospitals" provides only preliminary information about demographic characteristics. The Institutional Care and Economic Impact Planning Board recommended that additional reports be prepared and recommendations regarding the relationship between state and county responsibilities be submitted to the Legislature. The board also recommended increased emphasis be placed on supporting quality of care and quality of life in the current service system.

PAPER NO. 7: THE COST OF MINNESOTA STATE HOSPITALS

The legislation mandating the state hospital study and plan required the Long Term Health Care Commission to "evaluate the comparative costs to the state institutional and noninstitutional care for developmentally disabled persons." There are four parts to the cost report: (1) review of literature, (2) revenue and expenditures of state hospitals, (3) comparisons of money spent on institutional and community facilities, and (4) a needs approach to cost. Here are some highlights from the cost study:

Costs of State Hospitals:

1. Fifteen (15) years ago, the care given in state hospitals was custodial, and the cost per day was extremely low.

2. Court cases and federal standards resulted in better staffing. Costs increased.

3. In this same period, people with developmental disabilities were moving to the community. Costs continued to increase in the state hospitals because:

   a. The fixed costs increased because of fewer residents;

   b. Remodeling and construction occurred across the United States to meet federal ICF-MR standards;

   c. Staffing increased or stayed level in order to reach ratios;

   d. Unionization of public employees occurred which led to higher salaries;

   e. Inflation had an impact;

   f. The proportion of residents with severe/profound mental retardation increased as less handicapped people leave; and

   g. Indirect costs were added such as overhead and other state administrative costs in order to maximize federal financial participation.

Costs of Community Residential Facilities:

1. The number of group homes in the community has increased dramatically.

2. The ownership patterns can range from family, nonprofit, profit, chains, or systems. Family operations are the least expensive.

3. Community residential facilities need a standard chart of accounts and improved cost accounting.

4. Community residential facilities include capital items but not day programs or service costs.

5. Community residential facilities now serve all ages and all types of handicaps but the proportion who are most dependent is slightly lower than state hospitals.

6. Why average per diems shouldn't be compared between state hospitals and community facilities:

   a. Costs vary by type of resident (age, level of independence, services needed, and staffing needed). Children are always more expensive than adults. More severely handicapped people are more costly regardless of setting.

   b. Per diems do not contain the same items.

   c. No standard chart of accounts exists.

   d. No cost accounting system exists.

   e. There are several ways of determining costs which produces different outcomes in cost studies:

      — reimbursable cost reporting;
      — average per person costs;
      — fixed and variable costs;
      — unit costs; and
      — needs approach.

   f. In Minnesota, costs vary by geographic location (urban, rural); size (6 or fewer, 17 or more); staff ratios, and special certification.

Conclusions from Past Cost Studies:

1. Costs don't differ if both types of clients are provided full array of service. (Mayeda)

2. Community costs are fragmented across several accounts. (O'Connor)

3. By adding in day programs and medical services, the difference narrows. (Mayeda)

4. As a treatment site, the state hospital is not as desirable as a community setting. (Jones & Jones)

5. Impossible to compare because no standard chart of accounts and no standard cost accounting exists. (O'Connor)

6. We need to add in the issue of the "family" that provides care. The family may be the most cost-beneficial approach.

7. Reallocation of funds must be considered if numbers of people keep moving out of state hospitals.

8. The Pennhurst study concluded:

   a. State salaries and fringes are higher than community salaries and fringes.

   b. Community staff spend more hours of direct staff time per client than Pennhurst staff.

   c. There is a greater division of labor in state hospitals--more management, more specialists, and more medically oriented staff. Community staff do more jobs.

   d. Savings in community are due to use of generic services.

   e. How soon before community staff unionizes?

   f. How long will we expect a low paid, transient work force to serve more severely handicapped people in the community?

g. Rather than say community services are cheaper, we should say that we get more staff time for the money.

h. Some institution programs are less expensive than community; most institutions are more expensive; average per diem reflects a wide range of people.

11. The gross cost of Minnesota state hospitals for FY '84 was $159,045,479; 85.9 percent was for personnel.

12. Reimbursements totaled $120,594,420 from all sources with the largest amount coming from federal Medical Assistance ($52,656,694).

13. In 1980, expenditures for community services reached the same level as expenditures for institutional services for mentally retarded people. Since 1980, expenditures for community services have exceeded institutional services.

PAPER NO. 8: OPTIONS/RECOMMENDATIONS

The four options presented in this last report include:

1. Keep all state hospitals open but downsize.

2. Decentralize the state hospitals and begin state-operated, community-based services.

3. Increase efficiency and introduce elements of competition in all state hospitals.

4. Closure of one or more state hospitals.

On page 2 of this final report, we begin with a list of all the conflicting roles. Whenever interest groups discuss what is the state's role, there is a tendency to say, "the state ought to" forgetting that we do not have a blank sheet but rather a complex set of roles including:

— provide services;
— supervise services;
— monitor and license;
— guardian;
— defendent in court;
— employer;
— negotiator;
— provider of services to employees in case of closure;

— cost containment; and
— maximize federal financial participation.

OPTION 1: Continue operation of all eight state hospitals with staff reductions or downsizing in the mental retardation units.

— The mental retardation population will continue to decline because of the Welsch Consent Decree and the waiver.

— There could be as many as 582 fewer mentally retarded people by July 1, 1987, or it could be a minimum of 300 fewer people under the Welsch Consent Decree.

Effects on Employees:

— Because all types of staff levels are stipulated in the Welsch Consent Decree, the number of staff who could be reduced could be projected.

— The number of staff to be reduced totaled 644 positions.

— Based on historical experience, there are 1,640 separations because of turnover, retirements, deaths, and resignations. This number includes all employees including part time.

— It is our opinion that natural attrition can be used for downsizing as a first option compared to layoffs. Special exception is made to fill positions for health/safety and for Welsch compliance reasons.

— The next option is to make early retirement attractive through extension of Rule of 85.

— The next option is to extend the Rule of 85 and to add medical insurance benefits for people until they reach age 65 years. This

option is also less expensive than layoffs.

Effects on Buildings/Energy:

— The demand for living space is going down and yet capital costs will continue for remodeling/ renovation.

— If the population can use consolidated living space, then selected buildings can be declared surplus and sold, rented, or demolished.

OPTION 2: Decentralize the state hospitals.

We looked at Rhode Island's approach in beginning state-operated, community-based services. Our state AFSCME group prepared a proposal. The Department of Human Services also created a proposal included in this report.

Effects on Residents and Employees:

— Individuals would continue to move to the community.

— Employees would be allowed to bid on positions in community settings.

— Employees would be covered under collective bargaining and pension plan.

— Retraining would be necessary.

— Space needs would be reduced. Property could be declared surplus.

— The state might incur new capital costs in the community or existing housing could be used.

— Economic impact would be dispersed depending on relocation of residents.

OPTION 3: Improve efficiency and effectiveness of state hospitals and introduce elements of competition.

— Management information systems would have to be in place--chart of accounts, resident tracking, etc.

— State hospitals would generate revenue as a function of services rendered.

— Each state hospital would be responsible for program mix, budgeting, marketing, and rate setting.

— No catchment areas would exist.

— Counties and case managers would be responsible for payment of service.

Effects:

— Individuals and counties would have choice of using state hospitals at a prenegotiated cost of service.

— State hospitals would still be under the same policies.

— There would be more need for flexibility than civil service currently allows. Employees would be trained and transferred based on need.

— Each state hospital would have control over buildings. There would be an incentive to conserve. (This is a real problem area because the state bonds and every facility is not equal in terms of buildings.)

— Proceeds of sale of property would revert to state hospitals.

— Economic impact depends on skills of state hospitals:

  * rental value would approach fair market value;

* laundry could be a profit center; and
* per diems would reflect true costs.

Cautions about this approach:

— Concern about "dumping" most difficult clients or "creaming" or not providing service. The state has up to this point not rejected clients.

— True competition does not exist since the State Legislature has imposed moratoriums, sets funding levels, and has rate setting mechanisms.

— Counties have differing capacities to handle these new reponsibilities.

OPTION 4: Closure of the state hospitals.

— It is extremely difficult to terminate governmental organizations. There is little political incentive to do so.

— Terminations are usually accompanied by a budget crisis and/or an ideological struggle.

— There is a lack of systematic evaluation studies to determine impact of closure.

— Why closure doesn't occur:

* guarantees instant, galvanized opposition to the idea;
* benefit is minimal and means "fractionally lower taxes"; and
* incrementalism forces most programs to grow rather than be terminated.

Each state hospital was hypothetically closed for purposes of this study, and the impacts were assessed.

Effects:

— Based on past experience, if the state does not have time and money to develop community alternatives, the residents are sent to another state hospital. Consideration must be given to:

  * home county of each resident;
  * where are beds available?
  * do they match what the individual needs?
  * if not licensed or certified, how much money is needed for bringing into compliance?

— There are several research studies of effects on residents/patients and families. Results are mixed--changes in mortality, health problems, emotional changes, and adjustment issues.

— In the event of closure, we listed nine separate options for employees (pages 28-29). We also estimated the number of people who would take each option, including listing bargaining issues such as layoffs.

  We summarized the research on closure and effects on employees (lowered morale, stress, physical problems, emotional problems).

  We summarized the alternative uses of buildings, the cost of closure and calculated by hospital, the amount for severance, health benefits, unemployment compensation, and other costs such as heating, security, etc.

  Finally, each state hospital gave their own views about closure.

TESTIMONY SUBMITTED
TO THE
SENATE FINANCE COMMITTEE

SUBMITTED BY
THE NATIONAL ASSOCIATION OF
DEVELOPMENTAL DISABILITIES COUNCILS

COLLEEN WIECK, PH.D.
VICE PRESIDENT NADDC
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EXECUTIVE DIRECTOR, MINNESOTA GOVERNOR'S PLANNING
COUNCIL ON DEVELOPMENTAL DISABILITIES

September 19, 1986

SUMMARY

I. BILLIONS OF DOLLARS ARE SPENT, BUT WHAT ARE THE OUTCOMES? MEDICAID MAY FOSTER "RETARDING ENVIRONMENTS" AND "INACTIVE TREATMENT"

- While conditions in institutions have improved, isolation, removal from public and professional scrutiny, segregation and depersonalization do not facilitate quality care or quality living.
- The damaging effects of institutionalization on persons with developmental disabilities are well documented. The positive impact of community care in contrast with institutional care has also been well documented.

II. MEDICAID IS A POWERFUL INCENTIVE FOR OUT-OF-HOME PLACEMENTS

- Services that support families finish dead last in terms of funding compared to institutions and group homes.
- The Home and Community Based Care Waiver is an excellent beginning point to address this disparity but needs to be expanded.

III. RESTRUCTURING MEDICAID MEANS TOUGH ISSUES, INEVITABLE CHOICES AND POLITICAL HEAT

- Downsizing large residential facilities is inevitable for every state.
- The tough issues include: what to do with vacant buildings and public employees; how to mitigate the economic impact on local communities; how to involve citizens in a public process; and how to address cost issues of funding two systems, institutional and community.

IV. RESTRUCTURING MEDICAID MEANS CATCHING THE NEW WAVES AND FUNDING WHAT IS NEEDED AND WHAT IS POSSIBLE

- People with developmental disabilities should have new options and choices in housing such as sharing or owning living space.
- Supported employment should replace developmental and medical models of day programs.
- Consumers and family members should be empowered to make decisions about their lives, and funding from the Medicaid program should support individuals based on their identified needs rather than needs of the provider system.

Developmental Disabilities Councils across the country are in a particularly strategic position to understand the impact the Medicaid program has on the millions of Americans with developmental disabilities. Their role as planners and advocates brings them into daily contact with the problems and potentials of Medicaid.

NADDC appreciates the opportunity to discuss the impact the Medicaid program has on people with developmental disabilities and to suggest ways to restructure the program to meet the real needs.

I. BILLIONS OF DOLLARS ARE SPENT, BUT WHAT ARE THE OUTCOMES? MEDICAID MAY FOSTER "RETARDING ENVIRONMENTS" AND "INACTIVE TREATMENT"

We know a great deal from the research literature about the differences between institutional and community-oriented care for people with developmental disabilities. Medicaid tends to fund and upgrade institutional care.

Despite the investment of billions of dollars in such facilities, studies unanimously conclude that community care is more humane, results in startling improvements for individuals, is more closely aligned with Constitutional principles and is more cost effective than institutional care.

The damaging effects of institutionalization on people with developmental disabilities are well documented. Institutional conditions have led to

lawsuits in several states including Minnesota (Blatt, 1973; Blatt and Kaplan, 1966; Flint 1966; Goffman, 1966; Halderson v. Pennhurst, 1977; and Taylor, 1977.) In a 1977 accreditation survey of 48 state mental retardation facilities, 35 failed the test of minimal treatment quality, failing for the following reasons: (a) excessive use of chemical restraint and physical seclusion; (b) the impersonal nature of the physical environment; (c) excessive crowding in living spaces; (d) failure to provide comprehensive, interdisciplinary initial and periodic evaluation, program planning and follow-up and lack of developmental services; (e) lack of use of direct care personnel in training residents in self-help skills; and (f) failure to employ sufficient numbers of qualified personnel in direct care, medical, social, therapeutic, psychological and vocational training services. (Braddock, 1977) In April of 1986,the Senate Subcommittee on the Handicapped released a 250 page report showing that times have changed very little since the above findings and, in fact, some of the institutions visited were reminiscent of the appalling conditions of the 1950's and 1960's.

A number of studies have reported positive attitudes toward community living on the part of deinstitutionalized persons and their parents. The vast majority of individuals expressed satisfaction with their placements in contrast to their feelings about institutional life. (Scheerenberger and Felsenthal, 1977; Edgerton 1967; Edgerton and Bercovici, 1976; Aninger and Bolinsky, 1977; McDevitt, Smith, Schmidt and Rosen, 1978; and Birenbaum and Seiffer, 1976).

The third major body of research attempts to differentiate between various types of institutional and community facilities and to identify the

factors responsible for changes in residents' behavior and progress. Overall, the attributes which have been found to produce gains in adaptive behavior and general developmental growth are MORE LIKELY to prevail in smaller community facilities. Attributes include: individualized attention (Baroff, 1980); resident-oriented care practices (Balla, 1976; Baroff, 1980; King, Raynes and Tizard, 1971; and McCormick, Balla and Zigler, 1975); existence of personal effects, privacy in bathrooms and bedrooms (Balla, 1976 and Baroff 1980); community exposure and social interaction (Crawford, 1979 and Baroff, 1980); and experienced, trained direct care staff (Dellinger and Shope, 1978 and Baroff, 1980.)

There should be no doubt that smaller, home-like settings are preferable to large congregate ones in the face of such evidence.

II. MEDICAID IS A POWERFUL INCENTIVE FOR OUT-OF-HOME PLACEMENTS

For those people with developmental disabilities who have never been in an institution, we discover another major and cruel effect of Medicaid. Faced with inadequate resources and community supports, families are presented with powerful incentives to send their children away in order to receive Medicaid reimbursed services. Compared to the billions spent on out-of-home placements, less than 1% of the funding is designated for family support services.

There have been several studies on the effects on families when they have children with disabilities with respect to family structure (Fotheringham & Creal, 1974; Beckman-Bell, 1981; Paul & Porter, 1981; Willer & Intagliata,

1984; McCubbin, Joy, Cauble, Comeau, Patterson & Needle, 1980; Turnbull, Summers & Brotherson, in press); stress (Wikler, 1981; Shapiro, 1983) and coping (Wright, 1970; McDaniel, 1969; Neff aned Weiss, 1965). According to several investigators (Gruppo, 1978, Minde, Hackett, Killon & Sliver, 1972; Heisler, 1972), families of children with disabilities go through stages similar to the reaction to death. Despite improvements in services over the last 50 years, the major family problems have not changed (Farber, 1979).

Other research notes that services which support the family and child in the natural home have finished last when compared to other deinstitutionalization services (Loop and Hitzing, 1980). Disabilities create financial hardships for families because of costs for adaptive equipment, medication, therapies and lost income due to care-giving responsibilities. Family subsidies can be of great help in meeting these costs (Turnbull and Turnbull, in press; Patterson and McCubbin, 1983; Boggs, 1979; Moroney, 1981). Traditionally, however, in large measure due to the Medicaid program, resources become available once the handicapped child leaves home (Horejsi, 1979), substituting for, rather than supplementing the family (Moroney, 1979).

In reviewing the policy biases regarding supporting and not supplanting the family, one of the largest concerns is that policy makers are torn between the desire to provide for needy persons and the fear of creating uncontrolled programs. Policy makers are faced with questions of eligibility; whether to relate benefits to the characteristics of the family or to the level of functioning of the child with a disability; how to coordinate subsidies with tax policy; how to coordinate with other income maintenance programs; how to balance the competing demands for funds from state institutions and well-

established community programs. In addition, providing stable family support occurs in the unstable context of society where there are dozens of political, economic, social, cultural, technological, psychological and demographic variables affecting living arrangements.

In spite of these barriers, however, more than half of the states have adopted family support programs. Research supports what we see as the obvious benefits of family support: development at home is better (Poznanski, 1973); a family provides social development and emotional security (Schield, 1976);. children with disabilities have a right to be a member of a family (Vitello, 1976); and habilitative family care includes care, training and supervision in a planful manner (Horejsi, 1979).

The rising cost of residential placements has intensified the search for alternatives to out-of-home placements and a "rediscovery" of the family. While some argue that by focusing on cost, attention is shifted from civil rights and humanitarian concerns, the economics cannot be dismissed. While the states are struggling to find ways to provide family support services, Medicaid continues to offer only family supplantation services.

It should be mentioned here that the Medicaid Home and Community Based Care Waiver is an excellent approach which has begun to address the need to support rather than supplant families. However, the services under the waiver need to be dramatically increased and eligibility expanded. Expanding the waiver should be viewed as a stop-gap approach and policy makers should bite the bullet and solve the larger structural problams and totally eliminate the institutional bias of the Medicaid program.

III. RESTRUCTURING MEDICAID MEANS TOUGH ISSUES, INEVITABLE CHOICES AND POLITICAL HEAT

Downsizing of large facilities, whether they are institutions or community residential facilities, is inevitable.

The basic issues remain the same: what to do with buildings; what to do with employees; how to mitigate the economic impact of the change; how to involve the citizens of local communities in a public process; and how to implement the solutions. I hope to present some answers on how to approach these issues.

During the 1984 Legislative Session, the Minnesota DD Council of the State Planning Agency was given lead responsibility to conduct a study and propose a plan for state hospitals precipitated by (1) the sudden closure of Rochester State Hospital, (2) the Title XIX Home and Community Based Waiver which called for additional reductions in the mental retardation units, (3) the Welsch v. Levine Consent Decree, and (4) the proposed reorganization of the state hospital system by the Department of Human Services. Eight reports answered specific questions posed by the legislation. The study that we conducted involved all stakeholders and resulted in legislative action. I have brought copies of the executive summary of these reports for the committee.

The first priority in planning must be the individuals who are served, and the states must undertake independent verification of individualized needs and services to meet their needs. Other issues also need attention, such as economic impact, employee displacement, and alternative use of buildings. I

offer the following suggestions based on Minnesota's experience as you consider ways to restructure the Medicaid program and address the tough issues.

A. Alternative Uses of Buildings

Alternative uses of buildings must receive attention. One option for those in disrepair is to declare them surplus property. Our analysis shows that many states do not excel at disposing of surplus property. Generally speaking, state agencies report that they do not save money by using state hospitals for other government uses, due in large part to the condition and age of the buildings, energy and renovation costs.

Of the 31 institutions reported closed nationwide, none has been purchased by private industry. Over half have been converted to other types of institutions, e.g., corrections, veterans, geriatric apartments, colleges and religious organizations.

States should have a systemwide capital improvement planning process that recognizes long-term space requirements and the condition of the buildings. Remodeling should be avoided if the buildings are destined for closure. States should declare such buildings as surplus property, and demolish, if necessary, any buildings in poor condition.

States should develop an aggressive, coordinated marketing strategy for all potential alternative uses of large facilities. Specific decisions will require the active involvement of state, county and local agencies, and affected communities. States should ease any constraints on the sale of state

property to the private sector.

B. Impact on Public Employees and Local Communities

A critical area to focus on is the employees of institutions. Most legislative bodies are very concerned about the effects on the employees should a state facility close. States should gather information about the projected displacement of state employees because of deinstitutionalization, and the extent to which displacement can be mitigated through attrition, retirement, retraining, and transfer. The state should also survey state facility employees to determine future career choices.

Institutional closure can significantly affect a community's economy. The smaller the community and less diverse its commercial or industrial base, the greater the impact of any closure or downsizing. Economic impact is not only a function of where employees live and spend their money but also where they work in terms of commuting distance.

For purposes of Minnesota's report, there are three economic impact areas: 1) the primary impact zone is where 50% of the employees live; 2) the secondary impact zone is where 75% of the employees live (including the primary impact zone); and 3) the regional impact area is where at least 90% of the employees live and includes both primary and secondary zones.

We looked at the direct effect of hospital employment (employment as a percentage of total area employment; payroll as a percentage of total area wage and salary income; and estimates of unemployment by county); indirect

employment loss; state hospital purchases; effect of resident/patient spending; and effect of visitor spending.

States should develop alternative economic development strategies which require a cooperative effort between state and local officials. Economic impact zones may be one way to handle this issue in the future.

C. Public Opinion and Citizen Input

Public opinion and citizen concerns must be heard and a process developed to elicit them. Some strategies are: 1) holding town meetings in each affected area; 2) soliciting letters from the public and interested parties; 3) establishing an 800 phone number for a call-in day; and 4) distributing monthly bulletins on progress to announce meetings to interested individuals and organizations.

States must anticipate and plan for the economic chain reaction characterized by direct loss of institutional jobs, indirect loss of jobs because of slowed industrial growth, lowered gross community income, reduced retail sales, closed stores, fewer families, underutilized schools, increased taxes, higher utility costs, depressed housing market, and rising unemployment.

States must develop a process for public involvement during closure or reallocation of resources to prevent these factors from being barriers to implementing a deinstitutionalization policy.

D. Balancing the Cost Factors

In general, fifteen (15) years ago, the care given in institutions was custodial, and the cost per day was extremely low. Court cases and federal standards resulted in better staffing. Costs increased. During this time, people with developmental disabilities were moving to the community but costs continued to increase in institutions because: 1) the fixed costs were higher due to fewer residents; 2) remodeling and construction occurred across the United States to meet federal ICF-MR standards; 3) staffing increased or stayed level in order to reach ratios; 4) unionization of public employees occurred which led to higher salaries; 5) inflation had an impact; 6) the proportion of residents with severe/profound mental retardation increased as people with lesser handicaps left; and 7) indirect costs were added such as overhead and other state administrative costs in order to maximize federal financial participation.

During this same period the number of group homes in the community increased dramatically, the ownership patterns ranging from family, nonprofit, profit, chains, or systems. Family operations are the least expensive. Community residential facilities now serve all ages and all types of handicaps but the proportion who are most dependent is slightly lower than institutions.

Average per diems should not be compared between institutions and community facilities because costs vary by type of resident (age, level of independence, services needed, and staffing needed). Children are always more expensive than adults. People with more severe handicaps are more costly regardless of setting. Per diems do not contain the same items. No standard

chart of accounts or cost accounting system exists. There are several ways of determining costs which produce different outcomes in cost studies.

Some other important conclusions from past cost comparison studies are: 1) costs do not differ if both types of clients are truly provided the full array of needed services; 2) by adding in day programs and medical services, the difference narrows; 3) we need to add in the issue of "family" that provides care: the family may be the most cost-beneficial approach; and 4) reallocation of funds must be considered if numbers of people keep moving out of institutions.

The Pennhurst study concluded that: 1) state salaries and fringes are higher than community salaries and fringes; 2) community staff spend more hours of direct staff time per client than Pennhurst staff; 3) there is a greater division of labor in state hospitals--more management, more specialists, and more medically oriented staff (community staff do more jobs); 4) savings in community are due to use of generic services; 5) how long will we expect a low paid, transient work force to serve people with more severe handicaps in the community? 6) rather than say community services are cheaper, we should say that we get more staff time for the money; and 7) some institution programs are less expensive than community; most institutions are more expensive; average per diem reflects a wide range of people.

E. Options and Recommendations

There are four options presented in Minnesota's report. They may be seen as steps in a plan toward closure or as discreet decisions.

1) Keep all state hospitals/institutions open but downsize them.
2) Decentralize the state hospitals and begin state-operated, community-based services.
3) Increase efficiency and introduce elements of competition in all state hospitals/institutions.
4) Close one or more state hospitals/institutions.

The first option, downsizing, has effects on employees. Critical areas to plan for include: (1) projecting the number and types of staff reductions; (2) emphasizing natural attrition rather than lay-offs as a first option; (3) making early retirement attractive; and (4) adding medical insurance benefits for people until they reach age 65 years. This option is also less expensive than layoffs.

Downsizing also has effects on buildings and energy use. The demand for living space goes down, yet capital costs will continue for remodeling/ renovation. If the residents can consolidate living space, then selected buildings can be declared surplus and sold, rented, or demolished.

The second option, decentralizing the state hospitals/institutions, could involve looking at Rhode Island's approach in beginning state-operated, community-based services. In Minnesota, the American Federation of State, County and Municipal Employees and the Department of Human Services prepared proposals to follow this option.

Decentralization has effects on residents and employees. Individuals continue to move to the community. Employees can bid on positions in

community settings and can be covered under collective bargaining and pensio plans. Retraining would be necessary. Space needs would be reduced. Property can be declared surplus. The state might incur new capital costs in the community or existing housing could be used. Economic impact can be dispersed depending on relocation of residents.

The third option, improving the efficiency and effectiveness of state hospitals and introducing elements of competition, includes having: 1) management information systems in place; 2) state hospitals generate revenue as a function of services rendered; 3) each state hospital be responsible for program mix, budgeting, marketing, and rate setting; 4) no catchment areas; and 5) counties and case managers be responsible for payment of service.

Improved efficiency has the following effects: 1) Individuals and counties would have choice of using state hospitals at a prenegotiated cost of service; 2) State hospitals would still be under the same policies; 3) There would be more need for flexibility than civil service currently allows. Employees would be trained and transferred based on need. 4) Each state hospital would have control over buildings. There would be an incentive to conserve; 5) Proceeds of sale of property would revert to state hospitals; 6) Rental value would approach fair market value; 7) Per diems would reflect true costs.

States need to be cautious about using this approach. There is concern about "dumping" most difficult clients ("creaming") or not providing service. Minnesota has up to this point not rejected clients. True competition may not be possible dependent upon each state's rate setting mechanism. Counties may have differing capacities to handle these new responsibilities.

The final option, closure of institutions, while it ultimately should be the goal, is extremely difficult to do as a first step since there is little political or financial incentive to close them. Terminations are usually accompanied by a budget crisis and/or an ideological struggle. There is a lack of systematic evaluation studies to determine impact of closures. Closure usually does not occur because instant opposition is galvanized and the forces of incrementalism encourage most programs to grow rather than be terminated. States should first hypothetically close their institutions and assess and plan for the impacts as was done in Minnesota.

IV. RESTRUCTURING MEDICAID MEANS CATCHING THE NEW WAVES AND FUNDING WHAT IS POSSIBLE

The essential changes needed in Medicaid can readily be seen when one contrasts what currently exists and what should exist in serving people with developmental disabilities given the innovations that are fast becoming "state of the art." There are at least ten features of the present system which, if reversed, would solve many of the fundamental problems faced by people with developmental disabilities.

WHAT IS	WHAT SHOULD BE
1) Most dollars are tied to institutions such as state institutions and ICFs-MR	1) Most dollars are tied to to individuals.
2) Funding sources dictate where people live, consequently, many live in state hospitals	2) Individuals or guardians dictate where they live.

or ICF-MR facilities with few prospects for living in less restrictive settings.	People may leave these facilities if they choose.
3) Reimbursement mechanisms tend to discourage deinstitutionalization or independent living.	3) Reimbursement mechanisms promote deinstitutionalization and independent living.
4) Reimbursement mechanisms encourage families to place children with developmental disabilities in residential facilities.	4) Reimbursement mechanisms are flexible enough to allow families to care for their children at home.
5) There are no incentives to use less restrictive, less costly options. As a result, taxpayers pay more.	5) Incentives exist to use least restrictive, lower cost options. Taxpayers pay less for better service.
6) State maintains duplicative, two-tiered system of state institutions and community facilities.	6) Affords the opportunity to reduce capacity of the state institution system and the community residential system.
7) Virtually no screening mechanisms are in place.	7) Screening mechanisms are in place.

8) The reimbursement system is open-ended, fee for service. Few incentives for high quality providers.	8) The reimbursement system is limited, prospective. Some funding tied to provider performance.
9) People have no incentives to use high quality, low-cost, preferred providers.	9) People have incentives to use preferred providers.
10) People have few service options within the group home setting.	10) People have new choices such as contracting out or owning a share of the home.

A. Catching the New Waves

Innovative developments in services are currently occurring throughout the United States and federal policy should encourage and support their spread in areas such as citizen owned housing and supported employment.

In Brookline, Massachusetts, twenty-two units of condominium housing have been developed for adults with developmental disabilities. The units are integrated into the community and allow ownership of living space, friendship, and support of trained staff.

In the area of employment, individuals with mental or physical limitations have much to contribute to society. Many have the ability to perform valuable functions for employers. But, these individuals need challenging jobs, appropriate and adequate training, and consideration of

their limitations in the job matching and training process.

For many individuals, the major limitations have not been disabling conditions. Instead, they have been the stereotypes, expectations, and attitudes of individuals who do not have disabilities. These prejudices have resulted in individuals with disabilities being excluded from the experiences they need to qualify for and obtain jobs. They have also been victimized by a rigid model that has not kept pace with a changing society.

Throughout the country, new careers are being developed for individuals with disabilities, and technology is being applied to compensate for physical and mental limitations. These new approaches should be nurtured. However, there are far too many places where the old traditional models are being used and not working. Consumers, advocates, agencies, and employers are seeking more successful models.

The traditional vocational model, a continuum that requires an individual to move from evaluation to training, to a work activities center, to a sheltered workshop or a competitive job, has been unable to accommodate many individuals with severe or multiple disabilities. Most of these programs require that individuals meet entrance and exit criteria before they are considered employable. Many of the programs have become bottlenecked, resulting in waiting lists of individuals who need services. Individuals with severe disabilities have not moved through this continuum successfully.

Rather than require individuals with disabilities to adjust to an artificial continuum, it is feasible to train and support them in an actual

employment setting. This concept, supported employment, is more effective and less expensive than the traditional approach.

Supported employment is based on the following key ideas: 1) training is most effective when it is relevant, functional, and performed in the actual work settings; and 2) individuals learn best by modeling themselves after and learning from other individuals who are engaged in similar tasks. A great deal of natural learning occurs in this manner; this does not occur in segregated workshops.

Labels have very little value in developing learning objectives and support services for individuals with disabilities. Instead we need to develop functional analyses of the individual's skills and limitations, and compare them with the functional requirements of the job, allowing us to provide the supports required to compensate for a disability that inhibits job performance.

In the traditional continuum approach, staff members concern themselves with moving individuals from one segregated building to another. In the alternative approach, individuals are placed in the actual job setting immediately and services are provided as needed. Intensive services may be required initially, but as they are no longer needed, they are phased out.

Under the Consolidated Omnibus Reconciliation Act Amendments, supported employment is allowed under the Medicaid waiver. Medicaid should be restructured to discontinue "medical day treatment" in favor of supported employment.

B. What People Need

During the 1980's there has been a growing awareness of the rights of consumers and family members to make decisions about their lives, especially how funding decisions are made. Professor John McKnight of Northwestern University has noted that social service professionals have claimed the right to define what the problem is, what should be done about it, as well as to evaluate whether or not their solutions were effective. "Leadership becomes impossible when the claims of professionals are so comprehensive," McKnight says, because it strips clients of any personal sense of legitimacy or efficacy. The dignity of risk is lost. People become simply "clients" and society is encouraged to view them as social liabilities instead of social assets.

The growing empowerment of consumers comes into direct conflict with the Medicaid system as demonstrated by the following questions:

- Will individuals with disabilities be allowed to become as self-sufficient as possible or will they be encouraged to become overly dependent on professionals?
- Can the interests of caregivers and recipients be presumed to be the same?
- When conflicts arise between persons with disabilities and professional caregivers, whose interests will predominate?
- What is the impact of professional intervention (the formal system of care) on family and other (informal) system networks? Do present systems serve to supplement informal support networks or supplant them?
- Who decides how much care, and what kind, is to be rendered, when it

is to be proferred and the setting in which it is to be delivered?

- Are such decisions properly the province of the professional, individuals, government or the family?
- What happens to the ability to leverage change on one's own behalf, when reimbursement is provided by an absentee third party, particularly when a public subsidy is involved?

The restructuring of Medicaid along the lines presented will result in better services to people with developmental disabilities, elimination of the wasteful funding of two systems, and services based on the needs of the individual rather than the needs of the system.

In closing, I would like to add that Senator John Chafee's bill, the Community and Family Living Amendments (S.873), would, if passed, contribute greatly to the reforms we have recommended. We hope the committee will thoroughly study it.

A D D E N D U M

TO TESTIMONY SUBMITTED TO THE SENATE FINANCE COMMITTEE

SUBMITTED BY
THE NATIONAL ASSOCIATION OF
DEVELOPMENTAL DISABILITIES COUNCILS

COLLEEN WIECK, PH.D.
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COUNCIL ON DEVELOPMENTAL DISABILITIES

September 19, 1986

This addendum provides an executive summary of eight policy papers prepared by the Minnesota Developmental Disabilities Council in response to a legislative request for a plan regarding the future of state institutions.

Let me emphasize that Minnesota has plenty of plans, and some would argue that our state hospital system is overstudied. The problems with planning is that when major stakeholders are not involved, the planning is meaningless. Second, the Legislature can act without planning or can require planning and then not act. The study that we conducted involved all stakeholders and did result in legislative action.

PAPER NO. 1: MINNESOTA STATE HOSPITAL FACILITIES AND ALTERNATIVE USE (BUILDINGS)

The major focus of this study was an analysis of the general condition of the buildings and potential alternative uses of those buildings.

We examined several variables including the years the buildings were built, property size, building square footage, physical condition, plumbing condition, and electrical condition of the buildings.

Generally speaking, 43 state agencies reported to us that they do not save money by using state hospitals for other government uses rather than renting or building other facilities. This is due in large part to the condition and age of the buildings, energy costs, and renovation costs.

Of the 31 institutions reported closed nationwide, none have been purchased by private industry. Over half have been converted to other types of institutions, e.g., corrections, Veteran's, geriatric apartments, college, and religious organization.

PAPER NO. 2: MINNESOTA STATE HOSPITAL ENERGY USE AND COST

Energy consumption in buildings is affected by many factors including original construction features, efficiency of heating plant, severity of weather and type of heating fuel used. Meaningful comparison of energy use at the eight state hospitals was difficult.

We recommended that states should undertake energy conservation measures including: utilization of shared savings contracts; use of alternative fuels; purchase of electricity from wholesalers; separate metering of leased or rented buildings to the tenants; identification of surplus buildings for demolition to eliminate heating costs; and installation of improvements such as summer boilers.

PAPER NO. 3: A PROFILE OF MINNESOTA STATE HOSPITAL EMPLOYEES

The legislation authorizing the study was very concerned about the effects on the employees should a state hospital close. The legislation sought specific information about the employees: What is the projected displacement of state hospital employees because of deinstitutionalization, and what is the extent to which displacement can be mitigated through attrition, retirement, retraining, and transfer?

There are over 5,900 people, including part-time and intermittent employees working at our eight state institutions. Direct care staff are often female. The average wage is $4.00 to $5.00 higher than minimum wage. The length of service averages over eight years, and the separation rate varies by location.

The State Planning Agency conducted a survey of state hospital employees to determine future career choices. There were 26 questions, and 3,154 employees responded to the questionnaire. Regardless of how the question was asked, most employees indicated preference for public sector employment.

States may have to be creative in making early retirement more attractive rather than incur layoff costs. The portability of pensions may also need to be investigated at the state level to encourage transfer of employees rather than layoffs.

PAPER NO. 4: THE ECONOMIC IMPACT OF MINNESOTA STATE HOSPITALS

A large industry such as a state hospital contribute significantly to a community's economy. The smaller the community and less diverse its commercial or industrial base, the greater the impact of any closure or downsizing. Economic impact is not only a function of where employees live and spend their money but also where they work in terms of commuting distance.

Salaries of employees are the most significant factor in estimating community economic impact. The impact changes depend upon the dispersion of employees in a geographic area. Economic impact should not be calculated by multiplying total revenue by a multiplier effect such as "10" because it over estimates true impact.

Since most states have centralized procurement systems, local purchases by the institution are a small percentage of local retail sales.

If institutions are located in rural areas with high unemployment, alternative employment strategies are difficult to develop. Retraining and voluntary transfers of employees should be considered as a preferred economic development approach.

Alternative economic development strategies should not imply "filling up buildings with a newly discovered devalued groups such as people with AIDS, Alzheimer's, or those who are homeless."

Institutions located on prime property may be the first to close since economic impact will be lessened. It may be a wrong reason, but it is often more feasible.

PAPER NO. 5: PUBLIC OPINIONS ABOUT STATE HOSPITALS

A significant part of the study of the state hospital system was the development of a public process which provided Minnesotans with an opportunity to express ideas and concerns regarding the future of state hospitals and the delivery of services to persons with mental illness, mental retardation, and chemical dependency.

This public process involved three major elements:

1. The convening of nine town meetings, one in each area of the state served by a state hospital and one in the Metro area. (Over 5,000 people attended. There were 362 witnesses, and 80 separate organizations were represented.)

2. Soliciting letters from the public and interested parties who would express their views. (Over 433 letters were received.)

3. Receiving calls during a "toll-free call-in" day. A total of 202 calls; 174 favored state hospitals.

4. We also sent a "Dear Colleague" mailing once a month to 1,500 people giving results and announcing meetings.

The overwhelming message of the town meetings and phone calls was to keep the state hospitals open. The letters were split on this issue.

Here are the most frequently heard themes emerging from the town meetings:

Concerns about Patients and Residents:

- The special needs of residents should be the primary concern in planning the future of state hospitals.

- Persons most "difficult to place" because of

severe behavioral, physical, medical, communication, or multiple handicap problems are often served by state hospitals.

Views on Community Programs:

- Individuals have moved out of institutions and into the community. They have improved.
- Community programs (community mental health centers, case management, and community support programs) need more financial support.

Quality of State Hospital Staff and Care:

- State hospital staff and the care provided were described as caring, helpful, dedicated, the best, concerned, enthusiastic, skilled, superior care, warm, professional, and nationally recognized.

PAPER NO. 6: RESIDENTS/PATIENTS

Minnesota's state hospitals exist to serve people with mental illness, developmental disabilities, and chemical dependency. While there are many factors which will influence the future of state hospitals, a very important factor must be the individuals for whom they exist.

The state hospital study also found:

1. In 1960, a peak of 16,355 residents/patients were served in the state hospital system.
2. In FY '84, the average daily population of the state hospitals was 4,006 people: 1,230 people who were mentally ill; 2,182 people who were developmentally disabled; and 594 people who were chemically dependent.

We recommend that states should undertake independent verification of individualized needs and treatments to address those needs.

PAPER NO. 7: THE COST OF MINNESOTA STATE HOSPITALS

There are four parts to the cost report. Here are some highlights from the cost study:

Costs of State Hospitals:

1. Fifteen (15) years ago, the care given in

state hospitals was custodial, and the cost per day was extremely low.

2. Court cases and federal standards resulted in better staffing. Costs increased.

3. In this same period, people with developmental disabilities were moving to the community. Costs continued to increase in the state hospitals because:

   a. The fixed costs increased because of fewer residents;

   b. Remodeling and construction occurred across the United States to meet federal ICF-MR standards;

   c. Staffing increased or stayed level in order to reach ratios;

   d. Unionization of public employees occurred which led to higher salaries;

   e. Inflation had an impact;

   f. The proportion of residents with severe/profound mental retardation increased as less handicapped people leave; and

   g. Indirect costs were added such as overhead and other state administrative costs in order to maximize federal financial participation.

Costs of Community Residential Facilities:

1. The number of group homes in the community has increased dramatically.

2. The ownership patterns can range from family, nonprofit, profit, chains, or systems. Family operations are the least expensive.

3. Community residential facilities need a standard chart of accounts and improved cost accounting.

4. Community residential facilities include capital items but not day programs or service costs.

5. Community residential facilities now serve all ages and all types of handicaps, but the proportion who are most dependent is slightly lower than state hospitals.

6. Why average per diems shouldn't be compared between state hospitals and community facilities:

   a. Costs vary by type of resident (age, level of independence, services needed, and staffing needed). Children are always more expensive than adults. More severely handicapped people are more costly regardless of setting.

   b. Per diems do not contain the same items.

   c. No standard chart of accounts exists.

   d. No cost accounting system exists.

   e. There are several ways of determining costs which produce different outcomes in cost studies: reimbursable cost reporting; average per person costs; fixed and variable costs; units costs; and needs approach.

   f. In Minnesota, costs vary by geographic location (urban, rural); size (6 or fewer, 17 or more); staff ratios, and special certification.

PAPER NO. 8: OPTIONS/RECOMMENDATIONS

The four options presented in this last report include:

1. Keep all state hospitals open but downsize.

2. Decentralize the state hospitals and begin state-operated, community-based services.

3. Increase efficiency and introduce elements of competition in all state hospitals.

4. Closure of one or more state hospitals.

On page 2 of this final report, we begin with a list of all the conflicting roles. Whenever interest groups discuss what is the state's role, there is a tendency to say, "the state ought to," forgetting that we do not have a blank sheet but rather a complex set of roles including: provide services; supervise services; monitor and license; guardian; defendant in court; employer; negotiator; provider of services to employees in case of closure; cost containment; and maximize federal financial participation.

OPTION 1: Continue operation of all eight state hospitals

with staff reductions or downsizing in the mental retardation units.

- The mental retardation population will continue to decline because of the Welsch Consent Decree and the waiver.

Effects on Employees:

- Because all types of staff levels are stipulated in the Welsch Consent Decree, the number of staff who could be reduced could be projected.
- The number of staff to be reduced totaled 644 positions.
- Based on historical experience, there are 1,640 separations because of turnover, retirements, deaths, and resignations. This number includes all employees including part time.
- It is our opinion that natural attrition can be used for downsizing as a first option compared to layoffs. Special exception is made to fill positions for health/safety and for Welsch compliance reasons.
- The next option is to make early retirement attractive through extension of early retirement.
- The final option is to extend the early retirement option and to add medical insurance benefits for people until they reach age 65 years. This option is also less expensive than layoffs.

OPTION 2: Decentralize the state hospitals.

We looked at Rhode Island's approach in beginning state-operated, community-based services. Our state AFSCME group prepared a proposal. The Department of Human Services also created a proposal included in this report.

Effects on Residents and Employees:

- Individuals would continue to move to the community.
- Employees would be allowed to bid on positions in community settings.
- Employees would be covered under collective bargaining and pension plan.
- Retraining would be necessary.

- Space needs would be reduced. Property could be declared surplus.

- The state might incur new capital costs in the community or existing housing could be used.

- Economic impact would be dispersed depending on relocation of residents.

OPTION 3: Improve efficiency and effectiveness of state hospitals and introduce elements of competition.

- Management information systems would have to be in place--chart of accounts, resident tracking, etc.

- State hospitals would generate revenue as a function of services rendered.

- Each state hospital would be responsible for program mix, budgeting, marketing, and rate setting.

- No catchment areas would exist.

- Counties and case managers would be responsible for payment of service.

Effects:

- Individuals and counties would have choice of using state hospitals at a prenegotiated cost of service.

- State hospitals would still be under the same policies.

- There would be more need for flexibility than civil service currently allows. Employees would be trained and transferred based on need.

- Each state hospital would have control over buildings. There would be an incentive to conserve. (This is a real problem area because the state bonds and every facility is not equal in terms of buildings.)

- Proceeds of sale of property would revert to state hospitals.

- Economic impact depends on skills of state hospitals:

  — rental value would approach fair market value;

— laundry could be a profit center; and
— per diems would reflect true costs.

OPTION 4: Closure of the state hospitals.

- It is extremely difficult to terminate governmental organizations. There is little political incentive to do so.

- Terminations are usually accompanied by a budget crisis, and/or an ideological struggle.

- There is a lack of systematic evaluation studies to determine impact of closure.

- Why closure doesn't occur:

  — guarantees instant, galvanized opposition to the idea;
  — benefit is minimal and means "fractionally lower taxes"; and
  — incrementalism forces most programs to grow rather than be terminated.

  Each state hospital was hypothetically closed for purposes of this study, and the impacts were assessed.

Effects:

- Based on past experience, if the state does not have time and money to develop community alternatives, the residents are sent to another state hospital. Consideration must be given to:

  — what is the home county of each resident?
  — where are beds available?
  — do they match what the individual needs?
  — if not licensed or certified, how much money is needed for bringing into compliance?

- There are several research studies of effects on residents, patients, and families. Results are mixed--changes in mortality, health problems, emotional changes, and adjustment issues.

- In the event of closure, we listed nine separate options for employees (pages 28-29). We also estimated the number of people who would take each option, including listing bargaining issues such as layoffs.

We summarized the research on closure and effects on employees (lowered morale, stress, physical problems, emotional problems).

We summarized the alternative uses of buildings, the cost of closure and calculated by hospital, the amount for severance, health benefits, unemployment compensation, and other costs such as heating, security, etc.