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 *51/2* 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 NEED AND WHAT IS THE PERSON RECEIVING, 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 SUBMITTED
TO THE SENATE FINANCE
COMMITTEE

SUBMITTED BY
THE NATIONAL ASSOCIATION OF
DEVELOPMENTAL DISABILITIES COUNCILS

COLLEEN WIECK, PH.D.
VICE PRESIDENT NADDC
CHAIRPERSON NADDC PUBLIC POLICY COMMITTEE
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"

0 While conditions in institutions have improved, isolation, removal from public and professional scrutiny, segregation and depersonalization do not facilitate quality care or,quality living.

0 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

0 Services that support families finish dead last in terms of funding compared to institutions and group homes. 0 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

0 Downsizing large residential facilities is inevitable for every state.

0 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

0 People with developmental disabilities should have new options and choices in housing such as sharing or owning living space. 0 Supported employment should replace developmental and medical models of day programs. 0 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 commmunity 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; Wilier & 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 wellestablished 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 problems 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 pensioi 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.

b) 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.