STATE OF MINNESOTA
DEPARTMENT OF HUMAN SERVICES
Human Services Building
444 Lafayette Road
St. Paul, Minnesota 55155-38 15

April 19, 1988

Laura Wilcox, Hearing Administrator
United States Senate
Committee on Finance
Room SD-205 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Ms. Wilcox:

RE: Senate Bill 1673

Enclosed is written testimony I wish to submit in support of S.1673, Medicaid legislation submitted by Senator John Chaffee of Rhode Island. I understand this bill was heard by the Committee on Finance on Tuesday, March 22, 1988.

Sincerely.

SANDRA S. GARDEBRING Commissioner

Department of Human Services

cc: Senator John Chaffee
SD-567 Dirksen Senate Office Building
Washington, D.C. 20510

APR 1988
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DEVELOPMENTAL
DISABILITIES
DIVISION

STATEMENT SUBMITTED TO THE UNITED STATES SENATE COMMITTEE ON FINANCE REGARDING THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987 (SENATE BILL 1673)

BY

SANDRA S. GARDEBRING, COMMISSIONER
DEPARTMENT OF HUMAN SERVICES
STATE OF MINNESOTA

State of Minnesota
Department of Human Service
Human Services Building
444 **Lafayette Road**
St. Paul, Minnesota 55155

The State of Minnesota historically provided extensive services for children and adults with severe disabilities. In addition to traditional long-term care services, the State has developed services in less restrictive settings such as Semi-Independent Living Services for adults with developmental disabilities, a Family Subsidy Program for children with developmental disabilities, alternative care grants for persons who are elderly, and a variety of home and community-based waivered services. The Medicaid Home and Community Quality Services Act, S.1673, embodies many values which are consistent with Minnesota's efforts to provide persons with severe disabilities more normalized living environments, individualized services, and the opportunity to improve their capacity for independence and personal competency. S.1673 supports, and does not supplant, the natural home a value strongly reinforced by many of Minnesota's policies.

Minnesota was among the first states to use Medicaid funds to serve people with mental retardation or related conditions. We were one of the first states in the nation to develop Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) as part of our State Plan to create community residential service alternatives. Use of Medicaid funding has enabled our state to reduce the population of persons with mental retardation who are in state institutions (Regional Treatment Centers) from over 6,000 in the 1960's to less than 1,600 today.

Based on our experience, we have been able to draw some important conclusions regarding the merits of various methods of service delivery. For example, we have learned that the extensive use of ICFs/MR leads to service costs that are high. In 1987, the costs for Minnesota of the ICFs/MR programs alone was approximately $230 million. However, a number of individuals who are eligible for service in ICFs/MR can be served equally well using less costly alternatives such as home and community-based services under the Medicaid Waiver program.

Minnesota has found it possible to move many individuals from our state and private ICFs/MR, to more independent settings under our Home and Community-Based Services Waiver and to demonstrate both an increase in service appropriateness and cost reduction. People were often placed into our large state institutions from their family homes and can be returned directly to their homes or home like settings if sufficient support services are made available to their families or residential staff. For example, 60 of the 209 children and adults moved from our regional ICF/MR treatment centers last year have moved directly home or into home-like settings under our Waiver. We continue to identify individuals for whom such a move is possible. A January, 1988 analysis of client needs in our regional treatment centers indicates that at least 259 of the people still in these ICF/MR settings could be served in home and community-based services. The number of persons residing in our community ICFs/MR who could move to home and community-based services is much larger.

Minnesota's model Home and Community-Based Waiver for medically fragile/technology assisted individuals has repeatedly demonstrated that the most medically fragile people can be cared for in their own communities rather than in an intensive care unit of a hospital. Not only can they be cared for in their own homes, but their physical condition improves and they are able to do things that their physicians believed to be impossible.

For example, Patrick is a child who is ventilator-dependent. He spent the first three and a half years of his life in an Intensive Care Unit of a hospital. He would still be there today if not for the Waiver. Under the Waiver, he can live at home with his mother and attend school with his peers. His mother receives the nursing support she needs to manaage his care at home and at school.

stories similar to this have been repeated throughout the state. Fortuntely there are not a number of similarily technology dependent individuals. However, modern technology has saved the lives of many premature infants and severe accident victims. If we are willing to save these individuals, we must also be willing to support them and their families with the services that they need and allow them to live as normal a life as possible.

Despite the demonstrated success of community placements, fiscal disincentives to "non institutional" settings have existed since the inception of Title XIX funding and continue to exist today. Even the Home and Community-Based Services Waivers, which are an excellent alternative, do not allow movement of enough individuals to community services. Waivers are often viewed by parents and providers as temporary, due to Health Care Finance Agency's (HFCA) authority to approve, deny, terminate and/or renew the State's Waivers. States are required to demonstrate the services will be cost neutral as part of a complicated formula which is difficult to develop and which must be approved by HCFA of the Department of Health and Human Services. However, more traditional "institutional" services are included as a portion of a state's Medicaid Plan. Revisions to each state's Medicaid Plan are much less complicated that applications for waivers and are more within the control of each state. The stability of state plan services and ease of administration favor services that can be developed and supported using that mechanism. Thus, the system still seems to favor medical, institution-based services rather than home *and* community-based services. We believe the provisions of S.1673 are essential to further movement toward home and community-based services and therefore strongly support the bill. Rather than comment on each provision we would like to highlight a few provisions we feel are key to the provision of services in Minnesota.

SPECIFIC PROVISIONS

A. Provision of services based on need. We strongly support the provisions of S.1673 which enable us to provide service based on need. Several years ago, the parents of a ten year old child called Minnesota's Department of Human Services to inquire about facilities which could serve their daughter. They wanted to keep her at home, but were told by the county case manager that money was not available and that the only environment available where services could be funded and provided was a regional treatment center (large ICF/MR). After visiting the regional treatment center the parents decided instead to keep their daughter at home. Shortly thereafter, the daughter ran away from home, was sexually assaulted, and was subsequently placed in a regional treatment center. After two years there, Minnesota was able to use the Home and Community-Based Services Waiver to develop a foster home for the adolescent. She continues to live in that home today, successfully attending school, frequently visiting her parents at home, and vacationing with her parents. Obviously, this child experienced two years of unnecessary institutionalization and removal from her community. Making family support services available, based on need rather than on an arbitrary formula which is linked to existing service costs, would often prevent unnecessary institutional placements and unnecessary expenditures required for these placements. S.1673 would enable states to determine children under 18, living at home, eligible for services based on the child's income and resources regardless of the income of other family members in the same way we determine elegibility for services in our large ICFs/MR. This would eliminate an unintended bias toward ICF/MR placement where parents can place their children into our large ICFs/MR and, except for a limited fee schedule, these parents are relieved totally of the costs of their child's care.

B. Inclusion of case management in the array State Plan services. Minnesota and other states have been using case management services to provide for the individual service planning and oversite necessary to ensure quality services. Consumers are often overwhelmed by the complexity of program and eligibility requirements. They may be trouble accessing services and selecting the most appropriate services. This often results in a delivery system which does not target resources in a way that assures people receive what they actually need, no more and no less. S.1673 would include case management and an Individual Habilitation Plan as part of the required array of services, a position which Minnesota supports.

C. Provision of service options for states. The Medicaid Home and Community Quality Services Act allows states to have more flexibility to choose from the available service options those services which the state determines to be necessary and appropriate. If there is one generalization that can be made about people with disabilities, it is that they are not a homogeneous group about whom many generalizations apply. Similarly, each state has a unique set of circumstances within which it must operate. Establishing a core set of required services, but allowing flexibility in selecting other optional services, reflects an appreciation for differences in state needs and resource availability.

D. Elimination of reapplication process for waivers. Current HCFA regulations require states to use an arbitrary "cost effectiveness" cap and reapply at the end of each Waiver period. This policy has the effect of forcing state agencies to devote sizable resources to the process of preparing applications, computing formulas, and repeatedly defending the legitimacy of their requests. S.1673 eliminates the "cost effectiveness" computing formula cap and the need to apply and re-apply for waivers to provide services.

E. Inclusion of improved quality assurance mechanisms. As individuals move from institutional settings into small dispersed living arrangements, we have been impressed with how they benefit from these new living situations. Their parents, advocates, and interested citizens often share success stories with us. Neighbors, church members, school mates, and other community residents bus drivers, business people, scouts provide an informal network of friends who safeguard the quality of life for people with disabilities. However, there is a need for formal quality assurance mechanisms to oversee a system serving such a vulnerable group of individuals. We are supportive of the requirement contained in S.1673 for such a system.

F. Simplification of administrative processes and inclusion of administrative costs. Administratively, S.1673 provides more stable funding and simplifies the administration of home and community services. It also includes federal financial participation (FFP) for the administrative activities required by the legislation.

III. SUMMARY

Jason, who is five years old, lives in rural Minnesota. Two years ago Jason fell into a swimming pool and wasn't discovered for 10 - 15 minutes. He has all the medical labels that would classify him as among the most handicapped of children living in any institution. He no longer walks, can't talk, may or may not be able to see, and clearly does not respond to his world the way a child his age normally would. His parents have been struggling to get through the anguish of what's happened, to find the strength to support each other and keep the family intact, while at the same time trying to obtain services for their son. Luckily, they were able to get home and community-based services from Minnesota's waiver to support their efforts as a family. Unfortunately,

other children and the families have not been so lucky. They may live in a state which does not have approved home and community-based waiver services waiver or where the services under the program are so severely limited that their parents are left with no choice but to place the child out of their home.

Federal and state legislation have consistently moved in the direction of community services, however, funding has not always followed. The value of providing support for families has been expressed in concept, but it has not always been backed up by the allocation of resources to support the concept. Why will we pay thousands for institutional care but not hundreds for home care support?

The Home and Community Quality Services Act is not, as some have suggested, an attack on traditional models. It does not force states to close existing institutions. But it does create a holding pattern for the costs of such care to allow us to re-direct funding in a manner consistent with our stated policy of supporting people in their homes and communities. This legislation allows individuals and their families decide where they will receive needed services.

All of the major organizations representing citizens with developmental disabilities are in favor of passage of this bill. The involvement of so many key stakeholders presents a high degree of willingness to work together in the difficult implementation phase which accompanies any significant piece of legislation. This support will be particularly helpful in the five year planning process.

There are, of course, implementation questions that need to be addressed regarding this bill. The information tracking system and quality assurance provisions are both important, but sufficient time must be provided to allow states to come into compliance. HCFA's sanction authority will need to be established by Congress. In addition, the public hearings required to develop a plan will have some costs associated with them and we will need to consider how to deal with that issue.

Nevertheless, this legislation addresses issues in a humane way and targets money where it is really needed to establish home and community based services individuals and their families. Minnesota strongly advocates for passage of S.1673. It will help us to answer the questions parents and family members have been asking for years: "What happens if we are unable to care for our child or relative?" "Where does my child go after special education?" "Why do I have to be impoverished in order to receive supportive services?" This bill gives us freedom to allow for more normal living, working, and leisure time alternatives for persons with disabilities. Hopefully it will do so in a way that is not prescriptive or simplistic in assuming that all people require the same things.