TESTIMONY BEFORE THE SENATE COMMITTEE ON FINANCE, S. 2053, MINNEAPOLIS, MINNESOTA, AUGUST 13, 1984

My name is William C. Copeland, I am a resident of Minneapolis, and I have been working on the problems of financing and program of health, education, and welfare services for poor and disabled populations since the late 1950's. I have worked on these problems at the American Hospital Association, the Sister Kenny Foundation (now Interstudy), the Urban Institute, and as a private consultant.

In the mid-1970's, it became clear to me that -- given the plethora of funding sources, the many levels of government, and the multiplicity of private and public agencies involved, -- we needed a method which would allow us to deal in a budgetarily, politically, and programmatically orderly way with the financing of human services.

My own solution was the use of a continuum of services budget for each clearly-defined human services population. For each group -- the mentally retarded, the mentally ill, the physically handicapped, the frail aged, the population of children in trouble, the correctional populations, and the able-bodied poor -- we would develop the list of levels of care, the number of persons be cared for in each level, the cost of each level and the contribution of each major funding group. This approach has a number of advantages. It allows us to concentrate on one group at a time, with its own rather homogeneous politics, its own provider and advocacy groups, its own competing levels of care, and its own competing care technologies. By being able to list every level of care, every person in the care population, every person in the underlying population at risk, every cost for a person's care -- wherever spent, and every source of payment regardless of whether it is in a given legislature's or agency's budget or not , we are able to provide the basis for every legislature at every level of government and every executive at every level of government to make decisions about a particular target group in a way that allows a full understanding of program and fiscal (and, implicitly, political) impacts of one's own funding and program decisions.

If we organize our knowledge this way, our possible options become much clearer. When we organized our knowledge this way for a continuum of care for the mentally retarded (see the appended memos), a number of remarkable conclusions emerged from the analysis. They included the following:

1. The more restrictive end of the MR continuum is also the most expensive.
2. The intergovernmental fiscal incentives which existed at the time of the analysis, which still exist to some extent, and which S. 2053 seeks to change, in part, behave in odd ways:

a. Federal funding is fairly uniform along the whole continuum; however,

b. State legislatures and executives have the responsibility for constructing and changing the relative emphasis of the continuum of care (e.g., put less into institutions, put more into small community ICF-MRs, put more into family support programs). However, the only clearly identifiable Federal program they can work with is the ICF-MR part of Medicaid, which now runs at about $5 billion per year. The incentives in Medicaid have traditionally run toward large State institutions. So, the *perceived* incentives of State legislatures, prior to the coming of the home and community services waivers in the 1981 OBRA, ran toward institutional care.

c. Nobody is in charge of the other large pieces of funding for the MR. That is, the billions that go to the community, through SSI, SSDI, and Medicare, are Federally administered; and, there is no explicit Federal policy informing the use of these funds. (Example: for the 4.3 million persons on SSI and SSDI, the Federal government pays out $52.5 billion per year, as of fiscal 1985 for SSI, SSDI, Title 18, and the Federal portion of Title XIX; all of this money is untargeted with respect to both medical and vocational rehabilitation, in spite of the clear cost-effectiveness of both). At the same time, large amounts of funding are hidden in over-aggregated Federal-State accounts (which States might use creatively, if they knew those amounts were there), in Title XIX, Title IV-A, and Title IV-E of the Social Security Act. (Example: About 5600 children in foster family care in New York State under the Department of Social Services have measured IQ's of less than 70; this is the case in virtually every State; New York has done the research to find these children, so that they can build an appropriate program). As a result, no one, except in those States who have begun continuum budgeting, can make decent decisions about the care of the DD/MR populations. Those States which have begun the 1915(c) waiver process are clearly on the road to such decision-making.

3. Radical deinstitutionalization will save the United States several billion dollars per year. This arises from the fact that the total cost of community ICF-MRs is about 75 percent of care in State institutions; the total cost of program for persons in non-medical community residential programs is about one-half of the cost of State institutions; the average cost per person in the community, over all persons, is about 3/8ths of the average cost in the institution. The community costs include everything -- residential, medical care, education, transportation, social support, and leisure-time costs, so that community costs and institutional costs can be equitably compared. In our

original 1980 paper, Iversen and I used rather fragmented data to develop our simulations. When challenged on the realism of the assumptions in our model, we took later continuum data from three detailed State studies -- Minnesota, Illinois, and Ohio -- to test them. An additional memo laying out the data is appended to our testimony. The data from those three States make it appear that our original assumptions were largely correct.

4. The "woodwork" effect, if it occurs, will not be very large, for two reasons: there aren't that many more who are not currently in care; and the effect of community care, so far, has been to, possibly, lower the number in out-of-home care, not increase it. The current public-investment MR system includes about 1.2 million persons, about 350,000 of whom are currently in out-of-home care. If we look at the underlying population, there cannot be more than about 1.6 million persons (most of whom less severely disabled, if they can be classed as severely disabled at all). Thus, the population-at-risk is no more than 400,000, and is more likely about 100,000 to 200,000. Second, the effect of new community services in the 1970's was to hold the out-of-home care population to the same level in 1982 as in 1977. The paper by Brad Hill, et. al. would seem to indicate that the effect of new services in the 1972-1977 period (i.e., the new services radically increased the average age of movement from home into residential care -- from a median age of about 11 to one of 17, over a very short period) was carried on into the 1980's (see my attached paper on the fiscal effects of this change). Thus, if there is a woodwork effect of new community services, there is also an opposite effect, with the net result of holding out-of-home care members stable.

5. The basic conclusion: Since institutional services are more expensive than community services, and since changing the mix of services from a higher to a lower institutional emphasis does not have serious effects on the total numbers receiving some form of public investment, then a move to substitute home and community services for institutional services can only result in fiscal savings.

The implications for S. 2053.

1. S. 2053 is a major step on the road to the restructuring of incentives in the MR system in the right direction, and we should move a version of that bill into law. Within this bill, there are a number of changes that might be desirable. A number of them were developed by the National Association for Retarded Citizens. I would add two more.

   Over the past years, in every state, we have had to contend with those who argued for institutions because of the job needs of the institutional employees. Many, though not all, of those arguing in favor of institutions have (spoken or unspoken) the economic interests of the more than 200,000 employees of these institutions in mind. It is a problem which can be resolved. Following the example of Rhode Island and New York, I have argued that there is a natural future role for institutional employees, if they are willing to do community care development of family-scale programs, within reasonable distances of current institutions. If we develop a technique of set-asides of a significant fraction of current jobs for institutional employees, put strong retraining and continuing training incentives into our rate-setting systems, and move toward a role of the institutional employees concentrating on the more handicapped clients (for whose care they are now most responsible, because of an historic creaming policy in moving MR clients into the community), we would then have converted the incentives of the major holdout group to a family-scale program approach. In Minnesota, as Mr. Beer of AFSCME will note in his discussion, we are going to test out such an approach. If it succeeds, we should have our institutions closed more quickly than the ten years called for in the bill. I would add to the bill a provision for planning and study grants to State for planning the orderly movement of State institutional employees into community programs. The level of funding should be $200,000 to $500,000 per State, depending upon the size of the State system.

The second change would be to possibly consider taking institutions of 15 to 75 beds out of the bill. It seems to me clear that the case has been made on the fiscal and programmatic ills of the larger institutions. It does not seem the same for the mid-size institutions. We have some good indicative data on these institutions, but a clear case remains to be made on changes here. Instead, we should be financing a five-year program of well-designed studies of the 15-75-bed institutions, along the general lines of the studies carried out by Jim Conroy of Temple and John Ashbaugh of the Human Services Research Institute in Boston.

2. S. 2053 is concerned only with Medicaid financing, and -- as such -- does not go far enough. Its passage should be regarded as the basis for moving into a full continuum financing approach by the federal government. That is, the studies and reports defined by S. 2053 should be extended to include data on all publicly-supported MR/DD persons, at all levels of care, and regardless of public sources of payment. Thus, children on 94-142 programs, persons receiving SSI, SSDI, Medicare, Title IV financing, vocational rehabilitation services, crippled children's services, food stamps and other nutrition programs, housing assistance, Title XX funded services, State, county and city-funded services should all be included in each State's work on arriving at a manageable continuum of care. Once such estimates are made in a fairly reliable manner, the Congress

can then consider the development of a full capitation or prospective payment system for the States, for the MR/DD population -- with adequate incentives for community program built in.