

STATEMENT OF TESTIMONY

"The Community and Family Living Amendments of 1983"
S.2053

Respectfully Submitted
to the
SENATE FINANCE COMMITTEE

The Honorable David Durenberger, Chairman

by

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I wish to begin my testimony by thanking the Committee for the opportunity to discuss this very important piece of legislation without having to personally travel to Washington, DC. I applaud the Committee's desire to obtain a sample of views regarding S.2053 from various parts of the country. I am certain your field hearings will be of great assistance to improve S.2053 for the benefit of all disabled within the country.

The view I wish to present today is one from a small, rural state with a population of approximately 680,000. My state is primarily agricultural in nature with great distances between any urban areas. Cities in South Dakota have to be interpreted in the proper context of a sparsely populated, rural state. For example, the state capital of Pierre has a population of approximately 12,000 people. As the general population of the state is widely distributed; so too are the services to the mentally retarded/developmentally disabled (MR/DD).

South Dakota is a very unique state when viewed in the context of services to its MR/DD citizens. We remain a state with a very high rate of institutionalized MR/DD population per 100,000 general population (1982 statistics show South Dakota as the fifth highest state in the country). Yet, the same-year statistics show South Dakota ranking as the second highest state in the union in the area of providing small (15 bed or less), community residential alternatives to its disabled population. South Dakota is proud of its ability to deinstitutionalize its disabled population over the past 10 years. The population of our state facilities has decreased from 1,050 in 1974 to 555 in 1984. This is a reduction of over 47%. In the same period, services to MR/DD individuals in community-based programs have increased from 339 in 1974 to over 1,200 in 1984. These numbers, for large population states, seem very insignificant. However, for South Dakota, the numbers are very significant.

South Dakota has made, and continues to emphasize, a commitment towards serving its disabled people in the least restrictive, most normal community alternatives possible.

During the period of time prior to the actual introduction of S.2053, I was very excited about the possibility of legislation being introduced to correct some very large problems being faced by states such as South Dakota as they continued their efforts to develop community alternatives for those people currently institutionalized. Some of these problems are:

1) Current Medicaid legislation/policy continues to offer states substantial incentives to place and maintain disabled people in large, Title XIX-certified, long-term care institutions. Because of this financial incentive, many people still reside in our institutions who could benefit from placement into less restrictive, community-based settings.

2) Other than Medicaid funds, there are precious few dollars to assist states in providing for long-term care services for the MR/DD population.

3) The Home and Community-Based Care Waiver Authority is a very tenuous precedent established by the federal government. It is an option that many states (including South Dakota) have gambled on substantially in their efforts to deinstitutionalize and provide community service alternatives.

Therefore, I applaud Senator Chafee and the Association for Retarded Citizens of the United States for the concern and effort shown in bringing to national attention through S.2053 the unbalanced Title XIX incentives and the need to affect a change. While supporting many of the premises of S.2053, and most assuredly supporting the development of community-based alternative services for the disabled, I must indicate my opposition to the enactment of the bill in its present form. As written, S.2053 would, I believe, seriously undermine our state's continuing efforts to plan and develop appropriate community residential and day services for its DD citizens while still assuring quality

services for those needing to remain in our state institutional programs. I do sincerely hope that S.2053 can be modified in such a way as to be agreeable to the majority while still correcting the Medicaid problems mentioned earlier. If we maintain constructive discussion surrounding the bill with an attempt to understand each others' views, the substantial efforts put into S.2053 will not go to waste.

For South Dakota, the central policy question must be, "How can existing federal policy be altered to allow the state the greatest amount of flexibility to develop and support community alternatives?" The fundamental goal of every state residential system serving MR/DD people should be to assure that each individual is placed in the most normalizing, least-restrictive environment possible. I have serious reservations about S.2053's time-limited phase-out of Medicaid funding for long-term care residential facilities not qualifying as a "community or family living facility". My state is very much exploring the wide range of community living alternatives that can be developed for the disabled in our larger communities as well as (out of necessity) in our smaller communities. A federal mandate to move people from one service to another within a certain time frame accompanied by total or partial reduction of federal financial participation from one aspect of the total service system is not the answer. Rather, a clear, solid, and secure funding source for assisting states to develop community alternatives is the solution needed. I believe you already have a base for this solution in the Home and Community-Based Care Waiver Authority.

A proposal for modifying S.2053 is currently being discussed by the membership of the National Association of State Mental Retardation Program Directors. Although this proposal has not been formally adopted by the Board of Directors or membership of the Mental Retardation Program Directors, the alternatives being discussed make very good sense to the state of South Dakota. I believe

these proposals would provide that solid planning and funding base to allow my state to continue the process of deinstitutionalization. The Mental Retardation Program Directors' discussion proposal emphasizes the need for states to develop home and community care implementation plans. This implementation plan would be in lieu of S.2053's reference to facility size restrictions and institutional phase-out schedules. The home and community care implementation plan would have to be a solid commitment/agreement between the state of South Dakota and the federal Department of Health and Human Services. The plan would show how the state would reduce, systematically, the number of people in residential facilities with 16 or more beds to no more than 125% of the national median number of beds per 100,000 in the state's general population. The discussion proposal would recommend an alternative to the total Medicaid-support phase-out for residential facilities serving more than seven to ten people. South Dakota would very much support the alternative of disqualifying, for purposes of federal financial participation, the equivalent number of DD recipients in large Title XIX-certified facilities by which the state exceeds the 125% of the national median number in such facilities per 100,000 of the general population of the United States.

A most important recommendation of the Mental Retardation Program Directors' discussion paper is the recommended increase of the federal Medicaid matching ratio for home and community care services for states achieving a per capita rate of institutionalization (Title XIX-certified residential facilities with 16 or more beds) of below 75% of the national median rate for all states, based on the comparative number of beds per 100,000 in the general population. The Title XIX Home and Community-Based Care Waiver Authority has become the primary source of federal assistance to continue South Dakota's deinstitutionalization efforts. The financial incentive of an increase of three to five percent of

federal Title XIX participation would, in a rural, agriculturally-oriented state, convince many legislators to expand community alternatives. A substantial concern still exists among legislators, parents, and professionals that the passage of S.2053 as written would reduce the quality of services in the larger facilities during the phase-out period. However, if the bill were only to emphasize the increased matching ratio for home and community-based care services while allowing the states to collect current financial participation for the larger facilities during the period of deinstitutionalization, quality services would be maintained. South Dakota, and the nation, needs an S.2053 to restructure the Medicaid program to better serve the long-term care needs of its disabled. S.2053, as currently written, does not give South Dakota a clear assurance that federal funds will be available to support the needed community service system expansion. There seems to be an assumption that Medicaid funds that become available as a result of institutional phase-down will be automatically transferred to the community system. I would suggest that this "automatic transfer of funding" will more than likely not take place. I have no doubt, however, that South Dakota will actively pursue the development and expansion of community service alternatives, if:

- 1) South Dakota is assured of a financially attractive, flexible, and secure funding source with which to plan and implement the community services alternatives;

- 2) The state is assured that an appropriate level of secure funding is available to maintain clients in larger institutional programs during the deinstitutionalization period; and

- 3) Is assured that the flexibility is there to allow the planning for and implementation of community service strategies that are compatible to the current needs and conditions of a small, rural state such as South Dakota.

I sincerely hope the Committee considers the suggested modifications of S.2053 as I have presented today. With these modifications, South Dakota could support and applaud the passage of S.2053.

Thank you for the opportunity to share my state's views of S.2053. If I can be of further assistance, please call on me.