S. HRG. 98-1187

COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

FIELD HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON FINANCE

UNITED STATES SENATE

NINETY-EIGHTH CONGRESS

SECOND SESSION

AUGUST 13, 1984

Printed for the use of the Committee on Finance

U.S. GOVERNMENT PRINTING OFFICE
39-791 O WASHINGTON : 1985

5361-39

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COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

MONDAY, AUGUST 13, 1984

U.S. SENATE,
SUBCOMMITTEE ON HEALTH,
COMMITTEE ON FINANCE,
Minneapolis, MN.

The subcommittee met, pursuant to notice, at 2 p.m., at the Louise Whitbeck Fraser School, 2400 West 64th Street, Minneapolis, MN, the Honorable David Durenberger (chairman) presiding.

Present: Senators Durenberger and Chafee.

[The press release announcing the hearing and the opening statement of Senator Dave Durenburger follows:]

[Press Release]

SENATE FINANCE SUBCOMMITTEE ON HEALTH SCHEDULES A REGIONAL HEARING ON COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983, S. 2053

Senator Dave Durenberger (R., Minn.), Chairman of the Subcommittee on Health of the Senate Committee on Finance, announced today that the Subcommittee will hold a regional hearing on S. 2053, the Community and Family Living Amendments of 1983.

The hearing will be held on Monday, August 13, 1984, beginning at 2 p.m. in the Auditorium of the Louise Whitbeck Fraser School, 2400 West 64th Street, Minneapolis, Minnesota.

In announcing the hearing, Senator Durenberger noted that "Federally supported long-term care programs for the elderly and disabled traditionally have emphasized institutional care. As part of our ongoing hearings on long-term care, the Subcommittee is interested in the development of an integrated long-term care delivery system which provides an appropriate level of care, in an appropriate setting, on a cost-effective basis. The provisions of S. 2053 provide a basis on which to begin our examination of ways to provide for the long-term care needs of the Nation's disabled population. S. 2053 would seek to provide more individualized services for the severely disabled by shifting Federal medicaid funds from institutions for the disabled, primarily intermediate care facilities (ICF's) and ICF's for the mentally retarded, to community-based settings."

Senator Durenberger stated that the Subcommittee is interested in hearing from States in the region, providers, and consumers. The Subcommittee is particularly interested in comments on the possible benefits to be derived for the disabled and the medicaid program as the result of the proposed shift to community-based care; the feasibility and obstacles to providing such care; and the experience available from existing large institutions caring for the disabled as well as community-based facilities.

OPENING STATEMENT BY SENATOR DAVE DURENBERGER

I wish to thank you all for putting up with the tight timeline and coming here today to participate in this hearing on S. 2053, "The Community and Family Living amendments" sponsored by my dear friend and colleague, John Chafee. Like the hearing held in Washington last February on Senator Chafee's bill, this hearing has provoked a lot of discussion and raised a lost of concerns.

I think we all agree that funding for services for the mentally retarded and developmentally disabled should be structured so each individual will get the highest quality care in the most appropriate setting. Where our witnesses will disagree today is on the definition of the "most appropriate setting." We will hear a variety of viewpoints from our witnesses today and I hope we will all take away a sensitivity to the varied opinions on this very important issue.

We cannot avoid the issue of cast when discussing government funding financial assistance for the mentally retarded and other disabled persons. And Medicaid expenditures for Intermediate Care Facilities, a primary source of care for this population group, has become Medicaid's fastest growing category of expenditures, rising from less than $200 million in 1973 to almost $4 billion in 1983. Expenditures for ICF/MRs have increased at an average annual rate of approximately 34 percent from 1976 to 1981, more than double the 15 percent increase for all nursing home care expenditures and almost triple the annual growth rate for all Medicaid expenditures.

There are, however, no easy answers. I look forward to hearing from the witnesses today to hear about the state and community activities in providing and paying for services to the disabled. We will also hear from providers, researchers, and even recipients of care. I hope you will help us think through how we can ensure that the government pays the best price for the highest quality care in the appropriate setting. I thank all of you for coming this afternoon and taking the time to explore the proposal before us.

Senator DURENBERGER. Could I have your attention, please? Before we open the hearing we have a couple of housekeeping things to do. One, we have one row of chairs in the front row which isn't for the ushers, it's for the witnesses. So if there are any witnesses who are sitting back there, if you would, come up and take one of these chairs. It will facilitate the flow of the meeting.

Second, for those who are witnesses, the witness table right there is what you will be going to, and there are four mikes plugged into our friend from Washington here, our stenographer, who is making his very first trip to Minnesota at an advanced age. Let's all welcome him. [Applause.]

He is really a very tolerant guy, because he is the main fellow for the Senate Finance Committee, so he has heard a lot of headaches come and go, but he'll never tell a secret. [Laughter.]

But in the middle of the three witnesses is the only mike that is part of the amplification system. So if you want everybody else in the room to hear what you are saying, you'll have to use that mike. It will mean we will just move it around as we go from one on the panel to another.

Do we have most of our witnesses up front here? We haven't missed anybody?

I think I may just start. I think John is going to be here any second, and I'll introduce him when he comes. He is on a tough time schedule today.

Let me just bring the hearing to order for the sake of the record and indicate to all of the witnesses, in addition to the logistics here, we have written statements from almost all of you, and maybe those who we don't have statements from brought their statements.

Those statements will be made a formal part of the hearing record that actually started with our first major hearing on S. 2053 in February of this year. So you needn't worry when you get up there behind the mike that you are going to forget something, because it is already going to be made part of the record.

We have asked you to limit your formal statements to 5 minutes, and when the 5 minutes are up, since I'm not up for reelection, I'll be the mean guy and tell you to stop talking and I'm sorry. And that way both of us, and particularly my colleague here, will have the opportunity to ask questions, to amplify on the record.

Let me begin by thanking all of you for putting up with the tight time line that we had in putting this hearing together and for coming to participate in the hearing on S. 2053, which is called the community and family living amendment, that is sponsored by my dear friend and colleague John Chafee from Rhode Island who is here on my left.

John in his past life decided to be Secretary of the Navy which I don't think has much to do with retardation except its critics. John was also a Governor for a number of years. In fact I first met John when he was Governor of Rhode Island at the same time that Harold Levander was Governor of Minnesota, and those of us and particularly those of you associated with MARC were so involved in our deinstitutionalization and community living efforts here in this State in the late sixties. So he has that additional background.

The bill is his. He is responsible for all of the things you like and don't like about it. And I think all of us can agree that funding for services for the mentally retarded and the developmentally disabled should be structured so that each individual will get the highest quality care in the most appropriate setting.

Where our witnesses in Washington and other parts of the country and here tend to disagree is on what is the most appropriate setting for each of these individuals.

So today again we will hear a variety of viewpoints from our witnesses, and I hope we will all take away from this hearing a sensitivity to the varied opinions that all of us can have on an issue that is this sensitive.

We cannot avoid the issue of cost when we talk about it, much as we don't like to talk about those sorts of things, when we talk about government funding of long-term care services.

As you know, medicaid is the principal source of Federal financial assistance for the mentally retarded and other disabled persons. Medicaid expenditures for intermediate care facilities, a primary source of care for this population group, has become medicaid's fastest growing category of expenditures, rising from less than $200 million in 1973 to almost $4 billion in 1983. Expenditures for ICF/MR's have increased at an average annual rate of approximately 34 percent from 1976 to 1981, more than double the 15 percent increase for all nursing home expenditures, and almost triple the annual growth rate for all medicaid expenditures.

There are, however, even in those statistics, no reasons not to find better way to deliver services, and there are certainly no answers just in those statistics as to how to do it.

I look forward to hearing from the witnesses today to hear about the State and community activities in providing and paying for services to the disabled. We will hear from providers, from researchers, and even from recipients of care.

I hope you will help us think through how we can ensure that the Government pays the best price for the highest quality care in the most appropriate setting.

And I thank each of you, including the many who are not going to be testifying here today, for taking the time to help us explore this proposal.

With that, I will introduce my colleague Senator Chafee for his opening remarks.

Welcome, John, to the State of Minnesota.

Senator CHAFEE. Thank you very much, Senator Durenberger—Dave—for having this hearing and for inviting me out. I want to say you've got a lovely State here, and anybody who doesn't come to visit Minnesota should do so.

Also, I want to join in thanking all of the witnesses for coming. I know that some have traveled a good distance. Some will be unable to testify, because we had many more requests to testify than we had time for; but we did the best we could. I believe the witnesses we will hear today represent a good cross-section of views on the bill and the opportunities it presents.

Now, understandably, this bill has a high degree of controversy in some instances and understandably has evoked a good deal of emotion. Many critics of community-based homes for severely disabled and retarded citizens it seems to me are reacting not necessarily to the idea but many have deep fears as to what the future will hold.

I do want to make it clear that the purpose and the questions raised by S. 2053, the bill, are not whether institutions are bad but whether we can provide better care for those with severe mental and physical impairments.

It seems to me there is a strong historical bias toward caring for children and adults with mental and physical impairments in large institutions; that's the way we've done it, and many people feel that's the way we should continue to do it. And this bias toward the large institutions, of course, as Senator Durenberger has mentioned, is reinforced by medicaid reimbursement.

Simply because the bias exists, however, is no reason to ignore alternatives. Last November I introduced this legislation to provide a focus to the debate about the best form of care for the retarded and disabled. I think if everybody can keep their minds on that goal—what is the best form of care we can achieve?

There have been many discussions and numerous State court battles, but no national forum has existed to consider the experiences and needs of these individuals.

This legislation has provided the first major national forum where all interested persons from every State can come forward and discuss our national system of care for the severely disabled and mentally retarded. We will have other hearings in other parts of the country as well as here.

I chose the approach outlined in 2053 because I know that it will work. It is not simply some idealist's dream to believe that these individuals can flourish in a community setting regardless of the severity of their disability. It's a fact. We have seen it particularly in my own home State of Rhode Island as well as other parts of the country, where community care is working effectively.

States that have implemented this revolutionary system of care have shifted the emphasis of care to the individual, where it should be. Proper medical care is provided, as well as privacy, dignity, and room to grow and flourish. Supervision is focused not on keeping people quiet but on individual needs and fulfillment of individual potential. I think that is one of the key themes here: How can the individual most reach his or her maximum potential?

Now, no system is perfect. Many States have attempted to achieve a broader based community program and have failed. The causes of these failures are frequently cited in the testimony we have had, and in the letters and communications and meetings I have had. It seems to me they have arisen because of inappropriate settings, inadequate or improperly untrained staff, not enough funding, and the list goes on.

I welcome these criticisms, but I do not accept the conclusion that is too often drawn, which is, "See, it simply won't work." It seems to me we must address why it didn't work in those situations.

In most cases of failure, State planning and funding were inadequate. Those are exactly the reasons why this bill is so important. S. 2053 provides the means and the incentives to accomplish the goals of a higher quality of life for individuals with severe mental and physical disabilities.

When we introduced 2053, I said at the time and have repeated that this is a first step. Better options will no doubt emerge as we continue to discuss this program; this bill is not written in concrete. Otherwise, there would be no purpose in having these hearings.

We came here to learn, to receive suggestions from everybody here as to how we can do it better, and those suggestions will be incorporated into the legislation. But we've got to start somewhere, and this is the base.

I am willing to work with those who have legitimate concerns in order to get a bill passed which will be acceptable to most and accomplish the goal of providing a more comprehensive and humane system of care for the severely disabled and retarded.

My bill presents a challenge to all of us. The hope of a better future is one of the hallmarks of the American experience. For disabled and retarded Americans, that is what this debate is really all about—the hope and the optimism that their future, like the futures of the rest of us, can and will be better. I hope we can all rise to the challenge and improve this legislation, and make it work, and see the beginning of a new era—an era in which we can all be proud.

So, again, I thank you for coming, and I thank you particularly, Senator Durenberger, for arranging this. I look forward to the testimony.

Senator DURENBERGER. Thank you, John.

Our first panel will include Bradley Hill, University of Minnesota Center for Residential and Community Services, Minneapolis, MN, who is here on behalf of Dr. Charles Lakin; and Mr. William Copeland, Copeland Associates, Minneapolis, MN.

Gentlemen, I thank both of you for being here. As I indicated earlier, your full written statements will be made part of the record, and we trust you will be able to summarize from each in 5 minutes.

Mr. Hill.

STATEMENT OF BRADLEY HILL, UNIVERSITY OF MINNESOTA, CENTER FOR RESIDENTIAL AND COMMUNITY SERVICES, MINNEAPOLIS, MN

Mr. HILL. Thank you, Senator.

I am Bradley King Hill from the Center for Residential and Community Services at the University of Minnesota. I am presenting remarks today that Dr. Charles Lakin and I prepared—Dr. Lakin had to be out of town.

Our research center was established in 1976. Since that time we have completed many national studies pertaining to residential services for mentally retarded people in the United States. Our findings come primarily from the Administration on Developmental Disabilities and from the Health Care Financing Administration.

I would like to add parenthetically, also, that I am a foster parent for a severely retarded young lady and an active member of our local association for retarded citizens.

In 1977 in one of the center's first studies, we gathered data from more than 6,000 residential facilities, including State institutions, group homes, and specialized foster homes. In 1979 we sent interviewers to 75 institutions and 161 community residential facilities across the Nation. The interviewers gathered detailed data about facilities and about more than 2,000 mentally retarded residents, their abilities and disabilities, the services they needed and the services they received, and their family, social and leisure activities.

Two years ago, in 1982, we completed a national survey of over 15,000 public and private residential facilities and specialized foster homes throughout the United States.

We at the Center for Residential and Community Services are in general support of S. 2053. The prevailing attitudes and preponderance of research we feel favors small facilities. Little or no research seems to favor large facilities over small ones.

Among existing ICF MR's, the trend is already toward smaller facilities, albeit very slowly. The 10 to 15 year implementation period for S. 2053 would not be destructive to the service system, we don't feel. The current ICF MR program has evolved over a similar time period.

We have been unable to find bases for any claims we have heard of dumping made by people who are apprehensive about S. 2053. Over 8 years we have had frequent contact with each of the 50 States, and we haven't been made aware of a single instance in which mentally retarded people have been released without adequate provision of services.

We have found that there already are many small community-based facilities that serve the same health care needs, the same problem behaviors and handicaps, and the same severities that are currently served in institutions. The problem has been one of limited availability of community residences such as these.

We like S. 2053 because it does not limit access to funding from medicaid funds according to the number of ICF MR beds the States already have.

Today I would like to discuss in most detail the cost consequences of the Community and Family Living Amendments of 1983.

As presently written, we believe that as many as 1 percent of the U.S. population, or approximately 2.3 million people, might be eligible for ICF MR services. Other estimates range from 625,000 people to 1.2 million people. This would result in a tremendous cost shifting from States to the Federal Government. We are not saying that this cost shifting would be inappropriate, but we do feel it is important that you realize the implications of S. 2053 as it is currently written.

The historical problem with ICF MR funding is that it is based on locus of care. It is a Medicaid bed that is certified, and virtually anyone can be placed in a certified bed and therefore be eligible for medicaid reimbursement. The proportion of mildly and moderately retarded people currently in ICF MR programs varies from less than 1 percent in some States to 42 percent here in Minnesota. S. 2053 as presently written would change medicaid's focus to individuals; however, it would permit funding for a large number of developmentally disabled people.

There are currently 243,000 retarded people in State licensed residential programs; 143,000 in ICF MR's. Those are 1982 figures, which are the most current available.

There may be an additional 150,000 developmentally disabled people in generic programs such as nursing homes, foster homes, boarding homes, and as many as 2.3 million in all.

Senator **Durenberger**. Brad, we are right at 5 minutes, so you are going to have to come to the conclusion.

Mr. **Hill**. OK.

We think one solution to the eligibility problem would be to focus on resident characteristics. If severely or profoundly retarded people were served, for example, everyone currently in residential care could be served under medicaid with no net increase in cost.

Thank you very much.

Senator **Durenberger**. Thank you very much.

Bill Copeland.

STATEMENT BY WILLIAM COPELAND, COPELAND ASSOCIATES, MINNEAPOLIS, MN

Mr. **Copeland**. Thank you.

Senator Durenberger, Senator Chafee.

My name is Bill Copeland. I am a resident of Minneapolis. I have been working on problems of financing and program in health, education and welfare services for the poor and disabled population since the late 1950's. I have worked on these problems at the American Hospital Association, the Sister Kenny Foundation, the Urban Institute, sometimes at the Hubert Humphrey Institute of Public Affairs at the University of Minnesota, and as a private consultant.

In the mid-1970's it became clear to me that with the plethora of Federal programs and with the phenomenon of intergovernmental obliviousness in budgeting that characterizes the national legislature and the various State and county legislatures, that we simply could not make rational decisions about budgeting for human service populations without a different approach.

My own solution was one that said, "Let us use a continuum of services budget for each clearly defined human services population—frail, aged, mentally retarded, mentally ill, child welfare populations, and so on. We would develop a list of levels of care, number of persons to be cared for in each level of care, the cost of each level and the contribution of each major funding group such as the county, State, and Federal Governments. That allows us to concentrate on one group at a time, with a homogeneous politics, so that we don't have to worry about dealing with aging, mentally retarded, child welfare, and other advocates all at once in working on the budget. By being able to list every level of care, we find where the people are, what the flow is, what it costs us now, and what it is liable to cost us. Thus, we are able to provide to a given legislature or agency at every level of government a rational basis for making some decisions on funding.

If we organize our knowledge this way, our possible options get much clearer. I have appended some studies on the MR population which I started in the early eighties and which were given to people on the Hill, in DHS, and at OMB, and some of the conclusions that emerged from those studies were as follows:

The more restrictive end of the MR continuum is also the most expensive.

The intergovernmental fiscal incentives which existed at the time of the analysis and which still exist to some extent, despite the waiver movement, and which S. 2053 seeks to change behave in odd ways:

First, Federal funding is actually fairly uniform across the whole continuum; but the funding we see if we are in a State legislature is medicaid, which by the way is up around $5 billion now for ICF MR for 1985. And if we can only work with medicaid, the incentives of medicaid until we got the waivers were running toward institutions. So the perceived incentives for State legislatures, without additional information, were that they should put the money into institutions.

The next conclusion was that nobody is in charge of the other large and important pieces of funding for the MR; that is, for the 4.3 million severely disabled people under Social Security we spend about $55 billion in Federal funds alone, and there is no targeting of that funds for rehabilitation, there is no policy on that money, it is simply spent in several operations that don't talk to each other.

The next major conclusion: Radical deinstitutionalization will save the United States several billion dollars per year. We issued that result in 1980, we were channeled on it later. After that we found studies in three States in which we could show that our conclusions from the model we used were pretty much on target.

Therefore, since my time has run out, I will simply state that in general we support the objectives of 2053. There are some problems with it; we have written about those in our testimony. Thank you.

Senator DURENBERGER. Thank you very much.

[Mr. Copeland's prepared testimony follows:]

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.

Senator **Durenberger**. Brad, Bill Copeland said in his testimony—I think it was in the written part of his testimony—that we should not expect increased caseloads under S. 2053. You observed that there probably would be increased Federal costs in the implementation, since it would be obvious that utilization was going to rise. Could you try to explain that difference in your testimony?

Mr. **Hill**. I think so.

The use of ICF MR today has been largely a matter of State policy. Some States use it widely; some States don't use it at all.

Under S. 2053 we think also it would be made largely a matter of State policy, and that there wouldn't be anything to prevent States from incorporating their entire case management programs for all handicapped, all severely developmentally disabled people under S. 2053 to pull in a lot of day programming, a lot of all kinds of services, for basically anyone that they deemed appropriate.

Senator **Durenberger**. Bill, I want to thank you for some comments that you made about the multiplicity of Federal programs and the fact that we've got varieties like SSI, SSDI, medicare, child welfare, title IV, this whole thing, because it has been sort of a problem for me the last couple of years in the health area, whether I go into maternal and child health or I go in this area. We are dealing with a Social Security Act that was originally passed back in the early 1930's and sort of incrementally got added onto, but nobody ever seems to go back and try to integrate what it is we are trying to accomplish in that act. To the degree to which you can encourage us that there are opportunities to spend our money more wisely by perhaps just reexamining the authorization that we provide and aiming it at the kinds of population and needs we are trying to serve, that would be helpful to us.

Do you want to amplify a little bit on your comments?

Mr. **Copeland**. Yes, Senator. Thank you.

First of all, on the difference between Brad's and my estimates——

Senator **Durenberger**. Oh, I wasn't going to give you a chance to say that. [Laughter.]

Mr. **Copeland**. The difference really resides in the fact that the bill as written is rather open on eligibility, and my own assumption—unstated because of time—is that we would use an SSI or SSI-like definition. As long as we use that, I think we have quite adequate control and that we are not going to get a woodwork effect.

Second, in deciding how to work more rationally with the budgets for MR, the chronically mentally ill, the frail, aged, and so on—it seems clear to me there is an early-on information strategy that you can follow, and that is to expand on the information strategy that is not doing so well, that is better than anything we've got, that we find in the waivers, the home and community waivers. Essentially, ask the States to divvy up the medicaid into its proper programs. Medicaid is not one program; it's about six programs, and those should be reported. They should be reported to the Feds, they should be reported to the legislatures.

To some extent, HCFA is working on this in the so-called tape-to-tape project, and that I think could be encouraged, strongly encouraged, so as to give you a better feeling of what you're supporting.

Second, I think that HHS should be encouraged strongly, because it would have to be strong encouragement to get it done, to start linking the populations that they deal with in SSI, SSDI, medicare and medicaid; otherwise, until they do work on a linked information and budget basis, on your committee you will never be able to really know quite what you're doing.

Senator DURENBERGER. Thank you.

John?

Senator CHAFEE. Mr. Copeland, in your testimony on the bottom of page 2 you say that your conclusions are that the residential programs probably cost about three-eighths of the average cost in an institution. How did you arrive at that figure?

Mr. COPELAND. With our first simulation, a paper which is entitled "A Policy Memo," we did that with very fragmented data from Nebraska, western Massachusetts, and Franklin County, OH, and Minnesota, where we did have good data. Later we were challenged on whether our model had any reality by Mr. Geddings of the MR coordinators.

So we took three studies that we had done which were extremely detailed. In Ohio, Illinois, and Minnesota we did a very precise study of all funding, of all levels and all people in the continuum. There is a discussion of that in larger testimony that I mailed to the committee.

There we found that our estimates of three-eighths for the average unit cost for the community versus the institutions' 1.0 of costs were, if anything, slightly high. The community is probably 33 to 35 percent of institutions, on the average, as now run.

Senator CHAFEE. Well, that is a very important figure, and I might be getting back to you later on that, because obviously, as Senator Durenberger mentioned, the cost figure in this is not the objective in the program; the objective is to get the best possible care. But if you can get the best possible care at a reduced price, then you've really got something.

You mentioned also on page 4 that you felt perhaps institutions of 15 to 75 beds should be taken out of the bill. That seemed to be an indication on your part that they have a different roll? Could you expand on that briefly?

Mr. COPELAND. Thank you, Senator. From my own personal point of view, I think that the bill is right, going down to the below 15. However, it seems to me that the case is pretty well made on the large institutions. If we go through the whole literature, look at what has been done, the few tight studies and the many other studies that aren't so tight, the evidence seems to be that the State institutions really should be replaced. However, we don't have that kind of a case done in research on the medium-sized institutions.

So I only suggest that, because I don't believe that adequate research and discussion, public discussion, has been made in that area.

Senator CHAFEE. All right, fine.

Well, thank you both very much for coming. We appreciate it.

Senator DURENBERGER. Before the two of you leave, I have one general question, since you both know the Minnesota situation, and the Commissioner of the Minnesota Department of Human Services who submitted a testimony is not going to be able to be here to respond to his opposition on behalf of the State to some parts of 2053.

If I read his statement correctly, he said that Minnesota is opposed to 2053. He says:

> Measures to implement 2053 must be vastly different from State to State to allow the considerable differences that exist among the States. Minnesota and some other states will be faced with a monumental administrative task. And, third, the proposed sanctions for not complying with 2053 would be uniquely severe for Minnesota and the more than 4,500 individuals who will be affected.

And he seems to recommend that we consider alternatives which allow for management flexibility for States, and tie Federal financial incentives to individually determined State goals for program-size reduction.

Would either of you want to comment on the position of the State of Minnesota?

Mr. HILL. I don't know why he believes that it would be so much more difficult for Minnesota than any other State, unless it is because Minnesota has relatively larger numbers of people and larger facilities than some other States.

Mr. COPELAND. Let me say that working with States I sympathize with the Commissioner's request for flexibility, administrative flexibility, and I would certainly think that as much as could be designed into that bill ought to be in that line.

On the other hand, it looks to me that, given the way the financial incentives are working in this State, and given the way that people seem to be working together in this state—and Mr. Beer can comment more fully on this later—I have the feeling that we can probably close those institutions in 6 to 8 years with the full cooperation of everybody.

Senator DURENBERGER. All right, thank you.

Senator CHAFEE. One question.

Mr. Hill, in the testimony of Dr. Lakin, he states that research indicates that 35 percent of direct care staff in institutions leave their jobs in a single year. Do you agree with that statistic?

Mr. HILL. Yes, but it needs some qualifications. Not everybody working in large or small residential facilities are direct care staff. That was based on 1978-79 studies that we did at 75 institutions and 161 community residences. The day our interviewers left the facility, they left a sheet on which the administrators recorded for a 30-day period the number and characteristics of staff that actually left in that 30-day period, and that's where the 35 percent comes from.

Senator CHAFEE. Also, it may be the same people turning over. In other words, a 35-percent segment turns over, and a 65-percent segment stays constant.

Mr. HILL. Yes.

Senator CHAFEE. All right, fine. Thank you both very much for coming.

Senator DURENBERGER. Thank you both a great deal.

Our next panel consists of Thomas Scheinost, the director of the Office of Developmental Disabilities for the South Dakota Department of Social Services, and C. Patrick Babcock, director of the Michigan Department of Mental Health in Lansing, MI.

Let me express my appreciation to both of you for being here. As I indicated earlier, Commissioner Leonard Levine of the Minnesota Department of Human Services in St. Paul is not going to be with us today. He would have been part of this panel.

Mr. Scheinost?

STATEMENT OF THOMAS SCHEINOST, DIRECTOR, OFFICE OF DEVELOPMENTAL DISABILITIES, SOUTH DAKOTA DEPARTMENT OF SOCIAL SERVICES, PIERRE, SD

Mr. SCHEINOST. Chairman Durenberger and Senator Chafee, it is a pleasure to be here today, and I would like to thank you and the committee for the opportunity to discuss this very important piece of legislation.

I also would like to applaud the committee's desire to obtain a sample of views from across the State regarding S. 2053. I think it is a very, very important step.

The views I wish to present today are from a small rural State with a population of approximately 680,000 people. My State is primarily agricultural in nature, with a great distance between 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 and developmentally disabled.

South Dakota is a very unique State when also 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. The 1982 statistics show us as the fifth highest State in the country. Yet, those same-year statistics show South Dakota as ranking second highest in the country in the area of providing small—15-bed or less—community residential alternatives to its disabled population. We are proud of our ability to deinstitutionalize our population over the past 10 years; we have been able to reduce over 47 percent our institutional population during those 10 years while at the same period of time, the 10 years, increasing our community-based alternative services by well over 250 percent.

However, there are some very large problems that are being faced by states such as South Dakota as they continue their efforts to develop community alternatives for those people currently institutionalized. Some of these problems are:

One, current medicaid legislation and 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, many people still reside in our institutions who could benefit from placement into less-restrictive community-based settings.

Senator CHAFEE. As you know, this legislation would change that.

Mr. SCHEINOST. That's true.

Two, other than medicaid funds, there are very few precious dollars available to assist States in providing long-term care services for the MR/DD population.

Three, the Home and Community-Based Waiver Authority is a current, 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, Senator Chafee, I applaud you, and I applaud the Association for Retarded Citizens of the United States for the concern and the effort shown in bringing to national attention through S. 2053 the unbalanced title XIX incentives and the need to effect 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.

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, and I look forward to the time when I can say very honestly "I can support S. 2053."

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?

I have serious reservations about S. 2053's time-limited phaseout of medicaid funding for long-term care residential facilities not qualifying as a "community or family living facility."

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 that total service delivery system, is not the answer. Rather, a clear, solid and secure funding source for assisting States to develop community alternatives is the solution we need. 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, an organization I am currently holding the presidency of. 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.

Those proposals are presented in a little more detail in my written testimony.

I have no doubt that South Dakota will actively pursue the development and expansion of community service alternatives, but what we need in order to do that is:

One, an assurance of a financially attractive, flexible, and secure funding source with which to plan and implement community service alternatives;

Two, we need the assurance that an appropriate level of secure funding is available to maintain clients in larger institutional programs during that institutional phase-down period; and

Three, we have to be 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 have made my presentation extremely quickly in the hopes that we would have the time to discuss. Again, I thank you very much for the opportunity to present on 2053. I simply indicate that my position in opposition to the bill is definitely not in opposition to the concept, and I look forward to the time I can say I support 2053.

Thank you.

Senator DURENBERGER. Thank you very much. Mr. Babcock?

[Mr. Scheinost's written testimony follows:]

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

Thomas E. Scheinost
Program Administrator
Office of Developmental Disabilities
South Dakota Department of Social Services

August 13, 1984

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.

STATEMENT OF C. PATRICK BABCOCK, DIRECTOR, MICHIGAN DEPARTMENT OF MENTAL HEALTH, LANSING, MI

Mr. Babcock. Thank you, Mr. Chairman and Senator Chafee.

I am Patrick Babcock, the director of the Michigan Department of Mental Health, a State certainly larger than South Dakota, and we are here today in support of the basic concepts of S. 2053.

In many respects, 2053 reflects the Michigan experience. We have seen a number of policies in the last 10 years, including the special education policies to provide services for children from 0 to 25; we were one of the first States to pass the so-called "zoning override" legislation and a new family subsidy bill which took effect August 1 to provide a direct subsidy to families with severely disabled children when those children reside in their own home.

We have also seen an increase in community services in last several years, with day programming and family support and residential services.

The major impact of those policies has been a continuum of service which, while not complete, has put us along the way of recognizing the legitimate rights of developmentally disabled people and their families to remain in their own community. We have seen a decrease in the institutional population of nearly 57 percent when we include nursing homes, and for the State DD centers of nearly 65 percent. We have seen the closure of four facilities, and by the end of this year we will have closed three additional private facilities for a total of seven.

The community placement program and the community service program, while controversial, remain strongly supported in our legislature. Our plans are to place an additional thousand people over the next 2 fiscal years, while a third of those people will be in alternative institutionalization and the rest of them will be direct placement from skilled nursing beds and institutional settings where the people are inappropriately placed at this time.

The Governor has directed our department to establish as the operating policy that by the end of 1986 no developmentally disabled child shall be institutionalized in the State of Michigan when we obviously have the support systems in family subsidy in community services in place.

Our experience with the medically involved and behaviorally involved clients who have been placed is probably the most illustrative of the success of community placement. It goes back to your basic question, Senator, on where should people be better placed.

We have just closed the Plymouth Center as the result of a threat of a class-action suit, and of the 824 people who were in the Plymouth Center at the time the suit was brought, some 6 years ago, all but 32 individuals have been placed or matched to a placement within the next 90 to 120 days. Of those individuals, only 10 are so-called medically fragile individuals, and only 6 of those people fall below our current capacity, legal capacity, to serve people in community settings.

We are confident that that technology will change, and in fact that all of the individuals will be put in more cost-effective but more importantly more programmatically effective environments.

We are also confident that with 2053 and with the support of the Federal Government—but without it, with the current thrust of the State policy—that our institutional system in Michigan will be an artifact within 7 to 10 years, as we know it today. We know that, as we gain more experience with placing the so-called hard to place in the community, we will have more options available. We may have to change the community-placement system, but that is one of the beauties of that system—it is dynamic and is not stagnant. And in fact, it is manageable enough so that we can change and improve rather than be locked into the large-institution setting.

A major and critical component to any public policy concerning the transfer of services from institutional to community-based deals with the old building funding. We need a clear Federal policy, as we need clear State policies, to ensure that dollars follow the clients into the community, and that those dollars are available not only for people who leave the institutions but are available for people who have never been institutionalized and represent the so-called community-demand population.

In spite of our progress in Michigan, today still 30 percent of our mental health dollars spent for the developmentally disabled are spent in institutions serving less than 9 percent of our total caseload. In fact, we need to challenge that distribution of funds, because about 50 percent of those dollars are fixed costs that are not going to direct care but rather into maintaining the infrastructure of institutions.

As I said before, the residential placement and community service policiy is not without controversy. We have placed over 6,000 people throughout the State in over 1,500 small group homes and family foster care environments. While most of those homes have been well accepted, there have been fears and anticipations on the part of neighbors and in some cases on the part of guardians and parents, and we have had about 50 lawsuits. In all cases, the State's zoning overrider law and the State policy has been sustained for three basic reasons:

First, because the program works. We can demonstrate increased functioning levels; we can demonstrate quality of life for the people who were placed in our institutional system.

And we support our institutional system. We have the best intentions in the world; but, in fact, there is a difference in living in a small group home of 6 and having the individualized attention of a family environment and participating in community activities, than there is in living in a unit, well staffed, that still has 16 to 20 adults who are developmentally disabled.

Second, the right of persons to live where they choose is a fundamental civil right in our state under the Handicapped Civil Rights Act. They have that right irrespective of their handicap status, and that right should not be compromised.

Third, in case after case the initial resistance is diminished, and in fact we find now neighbors accepting the developmentally disabled as they identify those individuals as people, not as some clinical definition and as some population that has been out of sight and out of mind for far too long. And in fact we now have neighbors coming into group meetings about the development of new homes and the support of the new neighbors into the community.

We have been looking at and reviewing 2053 for the past 90 days or so, in order to provide information to our delegation in the Congress as well as to keep in communication with NARC, and we will have a formal report in mid-September; but our analysis to date indicates four or five areas that we think need to be strengthened in the bill:

One, eligible services must support persons in their own homes and also be made available to the community-demand population.

Two, labor protection should be written into the bill. We have an extensive labor-protection provision in the State of Michigan, in which we have been able to transfer employees, who have been affected because of community placement, into other jobs, into early retirement, or into relocated jobs with a severance pay process.

Three, we need a reasonable phaseout time period in order to phase out institutions, in order to ensure services available for both the institutional population as well as the community population.

Four, finally, there must be a clear commitment to maintain at least the current levels of Federal financial participation for services to the developmentally disabled.

Senator, in conclusion let me say that S. 2053 is essential because we need a clear national policy on the right of individuals to live in a community and to enjoy the benefits of their community, and that policy would not be abrogated by state boundaries. We see it as very much a civil rights question.

Thank you.

Senator **Durenberger**. Thank you.

[Mr. Babcock's written testimony follows:]

TESTIMONY ON THE COMMUNITY AND FAMILY LIVING AMENDMENTS ACT

C. Patrick Babcock
Michigan Department of Mental Health
August 13, 1984
Minneapolis, Minnesota

I am pleased to comment in support of Senate Bill 2053, also known as the Community and Family Living Amendments Act.

We in Michigan are proud of our accomplishments in developing a wide range of community based services for developmentally disabled persons.

During the last decade a number of major services have been established with the objective of maintaining persons with special needs in their community. These include passage of:

1. mandatory Special Education spanning the ages of 0 to 25, thus far exceeding federal requirement under PL 94-142;
2. zoning legislation which has made possible the development of nearly 6,000 community residential accommodations for developmentally disabled persons who either resided in institutions or needed an alternative to institutional care;
3. a comprehensive mental health code establishing the right of individuals to less restrictive environments and a strong recipient rights system for all individuals under the public mental health aegis;

4. and most recently, passage of the Family Subsidy Act. Effective August 1 of this year, the act provides a direct subsidy equal to the federal SSI rate to families with severely disabled children living at home.

These major efforts have been accompanied by substantial expansion in day programs, family support services and specific initiatives to provide permanent homes for all developmentally disabled children, preferably in their own natural homes if possible or in adoptive or long term foster care arrangements.

Perhaps the most visible effects of these programs have been the steady decline in institutional utilization. During the past nine years, the number of people residing in facilities including state institutions and nursing homes has decreased from 7,400 to 3,150. This has led to the closure of four public and three private facilities. The Department of Mental Health has been funded to place an additional 571 persons in fiscal year 1985 and has requested funds to accommodate the further placement of 505 people in fiscal year 1986.

In the State of the State message describing major policy direction for the Michigan's mental health program, the Department of Mental Health was mandated to put in place the service and funding systems required to eliminate the use of public and private institutions for all developmentally disabled children by the end of calendar 1986.

Our own experience in closing facilities and developing the more sophisticated community systems required by persons with greater physical and health care needs demonstrates that only a very small number of developmentally disabled persons provide a challenge for community systems that we have not yet learned to meet. A noteworthy example was one closure of Plymouth Center for Human Development through a consent agreement supervised by the federal district court. Of the 834 persons residing at the facility at the beginning of the court action, 32 have not been placed or matched to a placement due to their health care needs and required level of behavioral intervention. The initial group of persons at the Plymouth Center was highly representative of the persons throughout the state institutional system. Applying the resulting percentage of the non-placed population, Michigan, with a general population of over 9 million, would at most need only 300 institutional accommodations, applying our current treatment technology.

Unfortunately, fiscal and managerial demands that existing institutional systems command have skewed the long term positive effects of well-developed and managed community based systems on developmentally disabled citizens.

Even as we are transitioning from institutional systems, we see the benefits to persons who have never been institutionalized. In Michigan, this includes reinstatement of the family as not only the most appropriate caregiver and teacher of children and young adults, but of ongoing involvement in decisions and, when provided the opportunity, in the monitoring of the community system.

Notable examples of both a change in philosophy and policy has been the implementation of the permanency planning project. A little over a year old, the project has already successfully returned a number of children to their biological homes or led to adoption. More importantly, the project is demonstrating that when support systems exist, most families strongly desire to maintain their children at home.

For those with family members in the residential system, regional monitoring teams have been developed in the large Detroit metropolitan area. Small teams made up exclusively of family members or advocates monitor and evaluate group homes in a variety of areas, ranging from the normativeness of the environment to staff qualifications, recordkeeping and effectiveness of services.

A major component of the redirection of public policies concerning services for the developmentally disabled in the community is the transfer of resources currently used for institutional care. In spite of our progress in Michigan, 37 percent of the public mental health funding for the developmentally disabled is spent in institutions serving 9 percent of our caseload. A clear state and federal policy to redirect funding to follow the client into the community not only results in a higher degree of services for the individual, but also provides an opportunity to develop services for currently unserved or underserved individuals in the community.

The development of the community based system in Michigan has not been without its detractors. This has been especially true of our efforts at establishing small group homes and integrating them into typical neighborhoods. As stated earlier, Michigan has a comprehensive local zoning override legislation.

Although many homes are accepted at the outset, resistance in some communities has led to some 50 law suits challenging various provisions of the state law. The zoning law has been upheld in all cases to date.

The policy of developing small group homes in neighborhoods has withstood both legal and political challenges, principally because:

1. The right of persons to live where they choose is a fundamental civil right that cannot be compromised, and
2. in case after case where initial resistance is registered, the fear and apprehension of neighbors transitions to support or, as is the case in most neighborhoods today, disinterest within six months after the home is opened.

It is also noteworthy that these expansions of services have occurred during one of Michigan's deepest economic recession. This was made possible in large part because Michigan qualified all institutional beds at the beginning of the ICF/MR program and because of the relative cost effectiveness of community based vs. institutional services. The absence of federal funds for community services, however, will make this process increasingly difficult to finance. Thus, passage of S. 2053 is essential if the process is to continue. In effect, however, despite growing fiscal disincentives, Michigan has been doing as a matter of policy that which S. 2053 would mandate to maintain FFP and thus can serve as a success model from which the proposed legislation can be further refined.

Earlier this year, a state interdepartmental task force was established to review S. 2053 and recommend changes to the Michigan Congressional delegation and the National Association for Retarded Citizens on an ongoing basis. Although the group will not complete its work until mid-September, the intent of S. 2053 is clearly in keeping with our efforts in Michigan to continue the transition from institutions to community settings.

Among the preliminary recommended changes or enhancements of current provisions, the following are most critical:

1) Eligible services must, as a priority, support persons in their own homes and, when necessary, utilize smaller settings within their own communities, utilizing natural and generic locally available services to the fullest extent possible.
2) The legislation must include clear protections for employees who may be displaced as a result of facility downsizing or closures. Michigan has developed specific models for this effort. These include providing at least one year of notice of intent to close a facility, a restructuring of the pension system to provide for earlier vesting, severance pay provisions for staff in facilities targeted for reduction or closure, job referral programs and retraining opportunities.
3) The phase-out time period must provide sufficient time to both accommodate persons exiting institutions and those already living in the community in need of alternative residential programs and other support services.
4) Adequate protection and quality of care provisions for individuals in community settings, including their environment/habilitative programs and social support systems.

5) A clear commitment to maintain at least current levels of federal financial participation for services to the developmentally disabled as these services are transferred from the institution to the community.

As indicated previously, the process established to ascertain the impact of S. 2053 in Michigan will not be completed until mid-September. Our review and similar efforts in other states may lead to recommended modifications in eligibility criteria, service provisions or time frames.

It is essential, however, that the restructuring of the current Medicaid reimbursement system which fiscally both rewards and encourages use of large, often isolated and ineffective facilities occur as soon as possible.

We thank you again for this opportunity to comment on S. 2053 and look forward to working with the subcommittee.

Senator **DURENBERGER.** Let me ask both of you just one question. It is to explain, perhaps, the difference between Michigan on the one hand and South Dakota and Minnesota on the other hand.

As I listen to your testimony, I am not struck by any difference in commitment on the part of either of the States or even on exactly how to go about it. Everybody seems to be moving in the same direction.

Now, the question that occurs to me as I look at the testimony from South Dakota and Minnesota is that they are saying, Yes, we are moving in the right direction; we are using the medicaid home and community-based waiver initiatives to go in that direction; and just give us the resources to continue to move in that general direction because we think we know which way Federal policy is headed, but give us the opportunity to develop these different sorts of techniques on how to do it.

From Michigan I think I am hearing, the courts and commitment to civil rights, and other people said, "To heck with the demonstrations. You know, we know where we want to go; let's just go do it." And in a State of 9 million people they have gone and done it, and it has worked. So Michigan is saying don't be afraid of Senator Chafee and his 2053.

Am I missing something here in comparing the States?

Mr. Babcock?

Mr. **BABCOCK.** Senator, I think that local and State politics will clearly have an impact on any controversial policy, and that's why I favor Federal policy in this area, as we favor a State zoning override law rather than allowing local jurisdictions to decide where group homes should be placed, because they are going to the most vulnerable communities—that's just natural.

Currently a Federal lawsuit forced us to deal seriously with the policy that we had voiced support for for years and years in State government, but it did not mean much progress. Since that lawsuit went into place, in the ICFR funding—which also is a major impact—we have seen almost a two-thirds reduction in the population. We have had to take on some very tough political items; but because, frankly, of Federal support and because of the pressure of the lawsuit and the pressure, the legitimate pressure, of the activists, we did that. I don't think we would have.

Senator **DURENBERGER.** Where is the politics? There can be ARC politics, there are union politics, and there are small towns that have the big institutions that don't want to lose the business politics, just to name three.

Mr. **BABCOCK.** Well, a fourth one is labor resistance. And that's where you see pressure coming in local legislative districts.

I have been a council member in Michigan for almost 20 years, so I am in the political system, and it is easy to say, "No, we won't place a home here; we'll go to this other district or we'll go to this other part of the community." Once you start that process, however, you have a never-ending problem. So that has probably been the most prevalent issue, the neighborhood politics.

ARC, the parents and guardians, have been mixed, frankly, and both sides have some very legitimate concerns that need to be worked out and will be an ongoing educational process.

There are also the pressures of the budget. We do not support this program in Michigan becuase it is a money saver; in fact, it is a more cost-effective way to deliver services. Our numbers, Senator, are about 65 to 68 percent on the cost on the average of the placed population versus the institutional population, but that's a short-lived savings, because as we put the programs into the community and as that becomes the norm, there should be legitimate increases in salary levels. In fact, we just received a $4.5 million appropriation from the legislature to do just that, to upgrade the salary levels for group home staffs, to decrease some of the turnover vacancies that we have been experiencing.

Senator CHAFEE. Yes, but you would have had that salary request if you had had the institutions still existing.

Mr. BABCOCK. Oh, of course. Yes, of course, no question about it, Senator. In fact, we did it in order to get some parity, and we are still quite a ways away, as we look at the average salary for institutional staff versus community group home staff. We have moved for that irrespective of whether we were phasing out or not.

Senator DURENBERGER. Mr. Scheinost, this is one of the unique areas in which Minnesota and South Dakota apparently agree. [Laughter.]

What is wrong with going the Michigan-Chafee route?

Mr. SCHEINOST. I don't think there is anything particularly wrong. In fact, I believe very strongly in the direction that Michigan went and is going. I would support that wholeheartedly. Michigan is ready, they have the political situation available, and they are moving. And that is great. I've got a sneaking suspicion that the State of Minnesota or the State of South Dakota, once we would begin to see an avenue to run through in order to try to accomplish that same situation, we would be there moving along as fast as anybody else.

I think it is extremely important to understand the fact that right now—I am not sure of the exact numbers—I think there are something in the neighborhood of 40-some States in this country that have bought in, to one degree or another, to title XIX waiver authority.

And you know, when you stop and think about that, that States are buying into that—and as I said in my testimony, that is a terrifically tenuous situation—you are buying into something that is literally at the whim of the Secretary of Health and Human Services.

South Dakota is now about 4 months into our third and final year. OK? We have built a substantial expansion of community-service alternatives and a substantial deinstitutionalization using that waiver authority.

I think it is important to recognize that States are expressing a substantial amount of commitment to deinstitutionalize, or they would have never bought into that kind of a tenuous situation.

Senator DURENBERGER. But, whether it is in MR/DD or it is in just all the long-term care areas with our channeling, there is a different view in this Department of Health and Human Services than there has been in the past. In other words, there is a commitment to having States help us find person-specific and community-specific solutions to these problems. So it isn't quite the risk that it may have been a few years ago.

Mr. SCHEINOST. Well, you know, you talk to various agencies and various groups, and you hear many different reasons as to why the Federal Government has given us this home and community-based care authority. Oftentimes those different reasons don't quite——

Senator DURENBERGER. Some of us trust you—believe it or not. We trust you. [Laughter.]

I'm sorry—go ahead.

Senator CHAFEE. Mr. Scheinost, on page 5 when you say 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, I'm not sure what you mean by that. I thought we had taken care of that.

Mr. SCHEINOST. I have not read it at this point. I think what I am trying to indicate is that, unless you have a solid Federal source of funds, with perhaps some financial incentive——

Senator CHAFEE. Which we have.

Mr. SCHEINOST [continuing]. That says the State of South Dakota will have those funds available to develop the community alternatives, to develop the staff training, to develop the necessary purchase, construction, and so forth of the residential alternatives, then I believe that you are walking into something that many States will be forced to move into something that will not have the resources available.

Senator CHAFEE. But we don't provide money—the Federal Government doesn't provide money—for you to build your institutions. Or is the answer to that, you've got them?

Mr. SCHEINOST. They are there; that's true. That's true. Our system, Senator, in South Dakota is a totally private nonprofit system. We pride ourselves I think on the fact that the community system, the small apartments and so forth, that have been developed across the State have been largely done through a sizeable amount of different funding sources, including the Farmers Home Administration, HUD, and so forth.

Senator CHAFEE. Are most of them nonproprietary?

Mr. SCHEINOST. Yes. Yes, all of them are.

Senator CHAFEE. All of them?

Mr. SCHEINOST. All of them are.

Senator CHAFEE. Have you had trouble or has it been disconcerting to the work force at your institutions to go through this deinstitutionalization phase? Have they been able to catch on at jobs? Or what's happened. Did you mention you closed some down?

Mr. SCHEINOST. No. We have substantially reduced the numbers.

Senator CHAFEE. But you must come to a point where it is very uneconomical to run a sizable institution with one-third of the number of people it was designed for.

Mr. SCHEINOST. Yes. There is no doubt that South Dakota will face that, and probably in the near future. I think South Dakota will have to take a good hard look at what is the appropriate use of our State facilities. In fact, we are doing that right now. The staff obviously are disconcerted.

Although, I have to say this, that we feel at this point we are not overly staffed, in fact, we are not appropriately staffed, within our

State institutions. We can reduce a lot of clients out of the institution and still not release staff.

Senator **Chafee**. Mr. Babcock, I must say it is reassuring to have you here. I am always dismissed as, "Oh, Rhode Island is just a teeny-weeny State," and it's true, we are not very large. Therefore we can do these things. But there is great big powerful Michigan doing the same thing.

Mr. **Babcock**. We are not as powerful as we were at one time, Senator. [Laughter.]

Senator **Chafee**. Well, you look big to us, anyway.

Now, you indicated that you have gotten your institution population down substantially, but there is a group of about 300, I think you said, still there. Do you think there is a minimal—one of the discussions we constantly have in these hearings is, "Great program." But there are some people who just aren't fit to be placed in community homes; they must remain in an institution.

Mr. **Babcock**. Unfortunately, Senator, our current population in the State facilities is now about 2,100. Based on the Plymouth experience, if we extrapolated that experience through our system, there would be about 300 people who would need institutional care—the relationship with the 32 we have yet to place or match-replacement to the population—and about one-third of those individuals are medically fragile and the rest are behavioral cases. We think that we will be able to reduce that proportion even further.

Our plans are to reduce the State institutional population by about 350 to 400 per year over the next 5 to 6 years, and we have scheduled a 1,000 total placements. Again, one-third of those are community-demand individuals.

We feel that that would increase technology. It is something we learn through experience. We are careful in our placements that the medically impaired population will be safe. We may have to change the nature of those placements and build in—certainly build in—medical staff, as we have already tried to, and build in liaison to a community hospital, as we already have, but to better define those issues.

The problem is that there is no assurance that providing services for that population in an institution is going to do any good—or let me rephrase that, "is going to be better." In fact, we know that of people we have placed in the last 2 years, the people we never would have thought we would place 4 years ago that we have seen major growth and medical problems stabilize and in some cases improve.

Senator **Chafee**. Could you just come to a conclusion on that one thought? Where does that leave us? Is it your belief, as an experienced person who has been doing this, that we can get to zero?

Mr. **Babcock**. Following our technology today, I feel we can get down to 300 or so residents. I think that within 5 years, given the change in our support systems up to this point, I would say yes; we could get to zero. But the nature of the placement may be much different; it may not be a six-bed group home; it may mean that we challenge the traditional medical system and provide something similar to skilled-nursing care and in smaller groups of people rather than 50- or 100-bed nursing homes. I think we can, yes.

Senator CHAFEE. Well, do you think one of the answers might be a facility in the 15- to 75-bed area?

Mr. BABCOCK. Well, I would elect to go beyond 15 to 20 beds, and I think that because of the nature of the level of services and the relationship of staff to clients I would think a facility of 12 to 15 could be appropriate for that very medically involved population, or perhaps providing services and having that as an extended-care concept to a medical-surgical hospital.

Most of the people we have identified in this 300 medically impaired spend a good deal of their time at the University of Michigan Hospital and need access to that service and quality medical staff in order to monitor their progress.

Senator CHAFEE. I was interested in your statewide zoning provision. Has any other State got a provision like that?

Mr. BABCOCK. I think currently about 25 States do. Michigan was one of the first States—and, again, we've been challenged before the Supreme Court now, and we are confident we are going to win the case. We have had 50 challenges. We provide you with a synopsis of those, Senator.

Senator CHAFEE. Is that solely for this type? Do you have statewide zoning for any State facility?

Mr. BABCOCK. No. In fact, this is a unique provision of State law. It says, in effect, that local municipalities—townships and cities—cannot exclude a licensed adult foster care facility for the mentally ill or the mentally retarded or the aged if that facility is not within 1,500 feet of another facility, if in fact it meets State licensing qualifications, and there are provisions for local government then to also monitor the progress of the homes. So it is a zoning override bill.

Some of the lawsuits have dealt with deed restrictions, have dealt with businesses in the communities, and have dealt with a variety of folks.

Senator CHAFEE. Well, I appreciate both of you for coming here and giving your testimony; it is very, very interesting.

Let me ask you one final question, Mr. Babcock. You have obviously come from a highly unionized State where the union movement is strong, and obviously you have been required to deal carefully with the workers at your State institutions. And you said you have closed several—four—and somehow you worked through that successfully with the early retirement and the other points you mentioned. Could you touch briefly on that again?

Mr. BABCOCK. Yes. In my earlier political career I was State labor director, and I found myself after 3 years in that position going, in my first duty as State mental health director, to tell the 300 employees we were going to close their facility. In effect, we tried to put a package in place which, while not complete, has the basic elements I think of a sound labor policy.

First, we try to provide notice. Our optimal notice is a year, but we provide at least a minimum of 90 days, in order to allow workers to know that a change is coming, and we try to get as close to a year as possible.

Second, we have a transferability policy for other DMH, other mental health jobs, community mental health jobs, other State jobs, employed constantly in cooperation with the AFL-CIO to try to find employment elsewhere if that in fact is required. Of the 185 employees employed at Plymouth when we finally did close the facility, 90 days beforehand 156 were placed in other mental health jobs, particularly in the MI system that services the mentally ill. Only 13 were laid off out of that number. Michigan has a 10-percent unemployment rate, as you know, in this sector.

We have a severance package that has been negotiated for all employees, and I think it is probably the first severance package for all employees for any type of facility closure or plant closure, and that basically provides up to 52 weeks of severance pay for an employee who is not placed in another job before it goes in recall rates into State employment if they have at least 23 years of experience. It starts on a scale and works its way up.

Finally, the legislature changed the retirement law to permit that an employee who is dislocated because of a deinstitutionalization or the downside of a deinstitutionalization in the mental health system would only have to have 5 years of service to vest under retirement, rather than the normal 10, and provided us an opportunity—and it was our proposal in fact that they acted on—to allow the employee with 5 or 6 years, particularly the older person who wasn't quite eligible for retirement, to at least capture their fringe benefits.

We have continued to work in that area, because we hope that particularly working with the AFL-CIO in the job relocation grant that we'll able to train people for other jobs in the State economy as the economy improves.

Senator CHAFEE. Are your community homes mostly State owned and State run?

Mr. BABCOCK. No. There are only two in Michigan that are State owned and State run, and those are experimental homes for respite care. All of our homes, about 1,500, are run by nonprofit corporations or, in the case of family foster care, by a foster family. By the way, we ran into a problem with the IRS recently in the State, where they are trying to tax that foster care payment through a change in the Federal policy in that area that we are very concerned about.

Senator CHAFEE. But the rest are all nonproprietary?

Mr. BABCOCK. All nonprofit. There are a relatively few proprietary. We have a limit that any corporation can only have 12 homes, so we try to limit the maximum size of the corporations, and we have also separated the cost of leasing the house, the physical plant, from the contractor service in order to provide us flexibility. If a provider isn't working out, then we can maintain the site and change proprietors.

Senator CHAFEE. What is the typical organization that would run the nonproprietary? Would it be a church?

Mr. BABCOCK. It is actually—it ranges from organizations like Lutheran Social Services and Baptist Children's Home in Detroit, to primarily nonprofit corporations established by social workers and people who sometimes have been in our system who have moved into this area. And we have a very stringent contract with them that holds them to performance standards, to laws, to standards of management, and what have you.

Senator CHAFEE. Well, thank you very much. It has been very helpful.

Senator DURENBERGER. Did you say you are still having payments problems with the IRS?

Mr. BABCOCK. Yes, we are.

Senator DURENBERGER. Come on up here.

I thought I had taken care of that a year ago with a piece of legislation I authored.

Mr. BABCOCK. It just occurred within the last 6 months, Senator.

Senator DURENBERGER. Give us some details, to these folks over here.

Senator CHAFEE. Let me ask you one final question. I didn't get the point about former social workers who have set up a nonprofit home, and then go to work for it. Why would they go to all of that effort?

Mr. BABCOCK. Well, we have been fortunate, I think, because we are in a new service-delivery area We have been able to attract providers who are certainly not in the business for financial rewards. Our maximum administrative cost is running 90 percent of the total contract, so it would be about $9,000 a year on the average.

We simply have seen human service professionals establish nonprofit corporations similar to the settlement house movement in the twenties to provide that service, as we enter into a contractural relationship between Government and the private sector.

Let me just indicate that I would prefer that type of relationship. I think a problem with the State-run or county-run group home system is very similar to the problems we have seen in the State facilities—kind of an out-of-sight, out-of-mind concept, that the public sector is taking care of the disabled and therefore they are being cared for well. And we know from experience at Penhurst and Plymouth in our State that that isn't always the case.

Senator CHAFEE. Thank you very much.

Senator DURENBERGER. Thank you, gentlemen.

Our next panel is: Tom Beer, legislative director of the American Federation of State, County, and Municipal Employees, council 6, St. Paul; Patricia Crawford, Governmental Affairs chairman, Nebraska Chapter of the Mental Retardation Association of America, from Lincoln; and Dee Everitt, on behalf of the Association of Retarded Citizens of the United States, from Lincoln, NE.

Thank you very much.

Tom, you are first on our list, so why don't you go first, then we will go to Nebraska.

Tom?

You may proceed. Everyone is limited to 5 minutes, as you know. Your statements will be made part of the record.

STATEMENT BY TOM BEER, LEGISLATIVE DIRECTOR, AMERICAN FEDERATION OF STATE, COUNTY, AND MUNICIPAL EMPLOYEES, COUNCIL 6, ST. PAUL, MN

Mr. BEER. Thank you, Senator Durenberger and Senator Chafee.

My name is Tom Beer. I am with the American Federation of State, County, and Municipal Employees, Council 6, which represents approximately 3,500 State employees who work in direct-care capacities and support work in Minnesota State hospitals. I should add that Minnesota State hospitals are a combination of multidisciplinary facilities that treat the mentally retarded, mentally ill, and chemically dependent and two facilities exclusively at present for the mentally retarded.

Our international union has already provided testimony in Washington, as I understand it, on this bill, and I will not repeat that testimony other than to just summarize that it is our union's position that what is clear now is that a new system of care—whatever that be and whatever is developed—must be characterized by a continuum of care. And we believe that S. 2053, by withdrawing medicaid support from State institutions, would act to undermine many advantages that have significantly improved the quality of life for residents of institutions. I guess I am speaking not just about State facilities here but about facilities that would come under the bill that are in the community.

We don't believe it is appropriate that States should be encouraged to simply abdicate all direct care responsibilities either, which of course is a trend that is more or less pronounced depending on the State we are looking at.

In my prepared written testimony I really spent some time talking about the situation in Minnesota, from the standpoint of our union representing State employees, because I feel that it may be somewhat unique, or at least it is trying to pattern itself after some experiences in unions and States as employers in other parts of the country, and also because the legislation which my union was instrumental in getting passed in the 1984 session of the legislature was very much a first initial step for us in what we hope is a continuing process to deinstitutionalize staff of State hospitals as well as the residents of State hospitals.

I would like to summarize briefly the process of the legislation that we have put forward by saying that in 1984 a bill was introduced and passed, also incorporated into the Governor's budget, to allocate funds to the State planning agency in Minnesota, to look at the future of the State hospital system and more specifically at a variety of issues related to the quality of care, economic impact, employee status of future changes in the hospital system. This is very much a global effort, in that, as you might imagine, changes in the population of mentally retarded State facilities does have an impact on services that would be provided and are provided to other disability groups in those hospitals where multiple disability groups are served.

To date, the State planning agency has been carrying forward their study with, I believe, a high degree of participation input from most of the major actors in the State of Minnesota who are concerned with the care of the mentally retarded, our union included.

I guess the thrust of where we are coming from as an institution, as an organization, is that we believe there are strong reasons within the concern for the maintenance of the quality of care for—as I have said before—deinstitutionalizing staff.

I don't know what the long-range picture is for the future of State hospitals in Minnesota. My own personal opinion is that we are going to have State institutions, and probably ought to have them for a measure of flexibility in the delivery of care. However, I believe that by utilizing the resources that are there in the State hospitals presently, much of those resources, made up of the trained staff in the institutions, that greater strides can be made, frankly, toward deinstitutionalization.

Just in summary, we believe that State and public employees are not inherently evil or lazy or unmotivated, that they have invested in many cases many years of their time and this is a motivation to keep their job, that stability in the care-giving work force is one of the critical variables in successful communitizing of formerly institutionalized residents, and the staff of State hospitals offer this resource, and that many State hospital employees would be and are loathe to perform quality service for their clients if success guarantees the very loss of that job.

Senator DURENBERGER. Thank you.

Pat Crawford?

[Mr. Beer's written testimony follows:]

STATEMENT BY TOM BEER. LOBBYIST, AFSCME COUNCIL 6, AFL-CIO

Mr. Chairman:

Thank you for the opportunity to appear before you today to talk about various trends and policies in the quality of care of persons who are mentally retarded. My Union's membership is comprised of a large number of state employees whose direct responsibility is that very care, training and safety of retarded citizens in Minnesota State Hospitals. The over 3,500 state hospital employees who AFSCME represents in Minnesota, and on whose behalf I speak today, which to deliver a clear, unequivocal message to this committee and to all policy makers whether at Federal or State levels concerning the care of the retarded. This message is that state employees are concerned about the quality of care which the mentally retarded receive, and that quick fix, all or nothing proposals for the type of care given the retarded must be avoided. It is now clear that the unrelated events of limited economic growth and conceptual failure in the mental health system are changing the character of mental health care. The negative examples of change which we have seen include increasing numbers of homeless individuals [formally in state hospitals] and the self serving fast talk of entrepreneurs setting up community residences.

Two specific federal policies, one already enacted and the other now being debated are reference points for my Union's concern. S.2053, the Community Living Amendment Bill, is an example of the all or nothing approach. As introduced this proposal would eliminate all forms of institutional care - state operated and private, hospital and community.

The capacity of given states and localities to handle necessary transitions under this approach have not been carefully considered. Neither has the role of state hospitals been fully appreciated or the types of care such institutions provide been taken into account. AFSCME Council 6, AFL-CIO, must make it clear that we are not opposed to community placement of the retarded. What we oppose are proposals which masquerade as progressive steps when they are not. This includes schemes that emphasize a financial bottom line but have a dubious potential for assuring quality of care to the mentally retarded. Another such policy is the Title 19 Waiver (Section 2176, Omnibus Reconciliation Act of 1981) as designed by the Minnesota Human Service Department. Under their waiver,Human Service's Commissioner Leonard Levine proposed to reduce beds for the mentally retarded in the state hospital system by 1,000 by 1987. [11-3-83 Minneapolis Tribune]. A thousand beds is about half of the present state hospital system. The highly touted Title 19 Waiver assumes large numbers of Minnesota state hospital residents and sizable numbers of private ICF-MR residents can be transferred to less retricted settings.

To be sure, movement is possible. Less restrictive and less costly alternatives need to be developed. But the falacy of Minnesota's waiver is that,first it can quickly transfer residents to the community at substantial savings, and second that the needs of the more severly and profoundly retarded, many with behavioral problems will place no demand on community resources. If you were to talk to county social workers as I have you would quickly realize that resources are currently not there in the community to handle the wide range of problems of those now demanding services. Needs assessment and resource allocation for the most needy mentally retarded people have not been adequately considered under Minnesota's waiver. What problems does this create?

Two weeks ago I visited a non profit ICF-MR facility of ten residents in rural Todd County in Minnesota – about 50 miles from Brainerd State Hospital. About one-half of this group home's residents were former patients at Brainerd State Hospital. I spent three hours talking with the staff. They related stories of inadequate care; of custodial care; of non-existent staff training; of staff turnover near 100%; of frustration and despair. The staff of that group home saw the over worked county social worker once a year at case review time, and then not even at the group home itself. The spokesperson for the employees was a bright,young, articulate woman who summed up her deep concern by telling me about the latest resident who, released from the state hospital,just appeared on their door step one day. There was no orientation on him. No connection with hospital staff to help the group home work with the resident. She said bitterly that neither the residents or the staff were going anywhere. They were stagnating. I submit that this kind of situation is not unusual in Minnesota and that under the pressure of anticipated cost savings from the Title 19 Waiver - an assumption which is being looked at more and more skeptically by state officials - we will have more of this warehousing and standing still in the community in the future.

Long term care, be it residential or non-residential must be based on sufficient services and dollars following the needs of the mentally retarded. To say that services won't come cheap should be of no surprise. Community care which was designed to improve and replace institutional care at lower costs, turns out in some instances to cost more for more severly impaired people. And the upward trend for the cost of all services is rising. Title 19 Waiver euphoria not withstanding, the Rice County Minnesota private DACs recently asked the county board for a $2.00 per hour raise for their staff, citing the need to cut the high staff turnover which was harming continuity of service and the clients. The county board approved a dollar an hour raise.

The long and short of it is that costs in the community are approaching costs in the hospital. Costs in the community will increase and again this should be no surprise because sufficient, trained staff and adequate physical facilities and good management are not cheap. Quality care is not cheap. We can invest in an adequate system now or later. Failing to do it now will mean continuing to foster the hidden costs from high staff turn over and dead end programs.

My Union believes that a more sensible approach is to use old resources in new settings, thus avoiding the loss of trained state employees or the reduction of services to clients most in need. To these ends my Union had actively pursued a legislative effort modeled extensively after the experience of Rhode Island, Massachusetts, and other states that have chosen to transfer institutional resources into community care settings.

Rhode Island has done this by providing state operated, small living arrangements in homes and apartments for one to four mentally retarded persons. This has been done while maincaining state staff and existing Union contract benefits.

Dr. Robert Carl, Rhode Island's Director of Mental Retardation, has summarized that state's approach when he said: "I agree wholeheartedly that ... we must evacuate the institutions for the mentally retarded. Unfortunately, like most good thoughts, it is easier to say than to accomplish."

AFSCME Council 6 does not agree that the state hospital system should be abandoned, but never the less and for good reasons our Union took Dr. Carl up on his challenge by proposing in the 1984 Minnesota Legislature that our state begin to deinstitutionalize employees along with hospital residents. Like Dr. Carl we believe that: (1) state and public employees are not inherently evil or lazy or unmotivated and will perform as well as their training and supervision allows; (2) anybody who has invested five years in a job or career has some motivation to keep that job; (3) the stability in the care giving work force is one of the critical variables in successful communitizing formally institutionalized persons; (the transfer of staff and clients who know and like each other under circumstances that optimize staffs stability enhance chances of client success; (4) state institutional employees care about their charges and; (5) many state staff would be loath to perform quality service for their clients if success guaranteed loss of a job well done.

AFSCME in Minnesota was instrumental in 1984 in getting out legislature to take the first step in what we hope will be the successful transfer of state hospital clients and staff to the community. Our bill, which is appended, focused on the economic consequences of policies to eliminate the state hospital system and called upon state government to begin to address the situation with a comprehensive study of the future of the state hospital system, including the option of state operated and staffed community based services for the retarded.

Please note that this legislation is not a measure to accelerate or justify consolidation or closure of state hospitals or a measure to whittle this state's committment to the direct dare of the retarded. Our Union views this quite differently. We see this legislation and the administrative steps now being taken to implement the legislation as an opportunity to forge a new alternative, in which our membership is aggressively involved in developing its own future and in shaping the kind of quality care that mentally retarded people will need and deserve in the years to come.

Sec. 19. [246.023] [INTERAGENCY BOARD.]

Subdivision 1. [LEGISLATIVE POLICY.] *It is recognized that closure and consolidation of state hospitals have negative economic effects upon public employees and communities. It is the policy of the state that deinstitutionalization policies shall be carried out in a manner that ensures fair and equitable arrangements to protect the interests of employees and communities affected by deinstitutionalization of state hospitals.*

Subd. 2. [INTERAGENCY BOARD.] *There is established an interagency board to be known as the institutional care and economic impact planning board. The board shall consist of the following members: the commissioners of public welfare, administration, employee relations, economic security, energy and economic development; the director of the state planning agency; and other appropriate agency heads. The board shall be directed by the director of the state planning agency with assistance from the commissioner of public welfare in consultation with the other agency heads.*

Subd. 3. [STUDY.] *A comprehensive study shall be conducted by the interagency board to provide information on topics to include, but not be limited to, the following:*

(1) projected displacement of state hospital employees because of deinstitutionalization by number, location, and job classification;

(2) the extent to which displacement can be mitigated through attrition, retirement, retraining, and transfer;

(3) the development of cooperative arrangements between the state and local units of government in the carrying out of these goals;

(4) the necessary changes in the biennial budget to effect any fiscal and policy recommendations of the plan;

(5) the necessary interagency agreements among and between appropriate departments and agencies as needed to effect the recommendations contained in the plan; and

(6) the energy efficiency of all state hospital buildings.

Notwithstanding the provisions of sections 13.43 and 13.46, the state planning agency shall, for purposes of the study required by this subdivision, have access to private personnel data and private client data as necessary to carry out the mandates of this act until June 30, 1985.

Subd. 4. [PLAN.] *The board shall develop a plan. The plan shall include proposals which protect the general interests of employees and communities affected by the deinstitutionalization of state hospitals, including proposals that attempt to preserve employment rights and benefits, provide training and retraining of employees and, to the extent possible, promote the employment of these employees. In addition, the plan shall propose specific methods for assuring minimal impact on the economic life of communities affected by the deinstitutionalization of state hospitals. The plan shall provide specific direction with respect to the following:*

(1) retention of collective bargaining agreements including seniority, vacation, health insurance and other contractual benefits, and pension rights;

(2) maximum utilization of state hospital employees in the provision of noninstitutional services to the mentally retarded;

(3) negotiated agreements with exclusive representatives addressing job security issues, where deinstitutionalization causes displacement of employees;

(4) development of noninstitutional, state-operated or nonstate-operated services for the mentally retarded, including community-based intermediate care facilities for the mentally retarded, supported living arrangements, semi-independent living arrangements, day activity services, and other services;

(5) methods for ensuring that staff displaced by termination of programs at state hospitals are utilized to provide needed services within the continuum of care for individuals;

(6) alternative use of state hospital facilities made available by program closures;

(7) community retraining options for displaced personnel;

(8) methods for involving the following groups in the planning process: parents and guardians of hospital residents, community business and economic leaders, advocates, community providers, units of local government, and affected exclusive representatives; and

(9) preparation of an economic impact statement and alternative economic development strategies for each state hospital region likely to be affected by program reductions in the regional state facility.

Subd. 5. [REPORT; IMPLEMENTATION.] *The interagency board shall complete both the study required under subdivision 3 and the plan required under subdivision 4, on or before January 31, 1985, and shall present them to the legislative commission on long-term health care before February 1, 1985. Board members shall, to the extent possible, propose legislation for program implementation based upon the plan including, if appropriate, pilot demonstration projects.*

Sec. 20. [LEGISLATIVE COMMISSION ON LONG-TERM CARE.]

The legislative commission on long-term health care authorized by Laws 1983, chapter 199, section 17, shall:

(1) monitor the deinstitutionalization of state hospitals in accord with the plan developed pursuant to section 19;

(2) study the impact of state hospital deinstitutionalization on affected communities;

(3) ensure that displaced state hospital employees are provided opportunities for reemployment or retraining; and

(4) evaluate the comparative costs to the state of institutional and noninstitutional care for mentally retarded persons.

Sec. 5. STATE PLANNING AGENCY

State Hospital Plan	50,000	200,00

The director of the state planning agency may increase the approved complement by two positions. Any unexpended balance remaining the first year does not cancel and shall be available for the second year.

STATEMENT BY PATRICIA K. CRAWFORD, GOVERNMENTAL AFFAIRS CHAIRMAN, NEBRASKA CHAPTER, MENTAL RETARDATION ASSOCIATION OF AMERICA, INC., LINCOLN, NE

Ms. CRAWFORD. Thank you.

Good afternoon, folks. I am Patricia Kelly Crawford, and I thank you, Senator Durenberger and Senator Chafee, for the opportunity to be here this afternoon.

I am speaking today for the Mental Retardation Association of America, Nebraska Chapter, and for the Congress of Advocates for the Retarded, Inc., of which I am a director. These two organizations are comprised basically of thousands of parents.

I am a parent of a profoundly retarded young man who is now 23 years old. He lived at home until he was 14, attended community-based programs, and when he reached the age of 14 our family—my husband and I and our other family members—determined that we couldn't provide the structure and the programming, the full-time programming, that Matt needed in our home and in the community programs, and we placed him at the Beatrice State Developmental Center, our only State institution for the mentally retarded in Nebraska. We have been very, very pleased with the care he receives there. And unfortunately, because of his profound retardation, he has no speech. But it is fairly easy to know what he likes and doesn't like most of the time, and if he could be here today and tell you, I'm sure he would say "I prefer to stay here where I am," because he gets the programming and the care. Don't ever believe a word of it—people tell you that institutions are impersonal or bad or any other thing. He has an interdisciplinary team of which I am a member, and it is amazing to me when we go for our meetings how well those folks know him.

The organizations that I am speaking for strongly are opposed to S. 2053 because it would remove this one segment of the continuum of care that we believe is necessary for the medically retarded needy people. Their IQ's range from zero to 70, and it seems so obvious to me that one mode of care wouldn't serve such a range of abilities and disabilities. We tried that at the turn of the century when the Beatrice State Developmental Center was built and came to know in the sixties that that certainly was not the answer for our own mentally retarded people, and I would hate to see us, one century later, go back to the same thing, one mode of care, for a huge group of people.

It is so important to recognize that these people are individuals and have individual needs, and that they aren't just a member of some group which treat them all alike.

I have brought for the subcommittee use two 15-minute cassettes showing the Beatrice State Developmental Center—a picture is worth a thousand words—two sides of the tape. I hope you will take them and use them individually or collectively, or whatever.

I thank you very much.

We feel that S. 2053 isn't a mandate to close institutions, but it certainly is a method to close institutions. And we have been through that in Nebraska during Jim Atcheson's administration. We have had litigation in an attempt to close the institution, and fortunately we still have our State institutions, plus three small institutions operated by the Lutheran Church. We certainly are in favor of expanding community-based service for the folks who can benefit from it; but it is absolutely essential to realize that not everybody can benefit.

What are you going to do if we find later, if this bill passes in its present form and we have eliminated part of the continuum of care, we have eliminated the choice for families, and have ignored the differences in people who happen to be mentally retarded? Then where are we?

In 1980 there was a Touche-Ross study in Nebraska to determine the cost in community-based programs and in the Beatrice State Developmental Center. The Touche-Ross people determined that the client characteristics that determine cost are the level of retardation, mobility, behavior, medical needs, and self-care skills, and that the staff time was by far the greatest cost factor.

Since basically the professionals in both community programs and at our institutions use the same sort of techniques in caring for the folks, it doesn't make sense to think that these people are going to change dramatically—the people who can't walk or talk or toilet themselves—just simply because you have moved them to a smaller place.

Thank you very much.

Senator DURENBERGER. Thank you.

Let me also indicate that Ms. Crawford's statement which was submitted to the hearing in Washington was made part of the record at that time.

Thank you.

Dee Everitt?

STATEMENT OF DEE EVERITT, PRESIDENT, ASSOCIATION OF RETARDED CITIZENS OF THE UNITED STATES, LINCOLN, NE

Ms. EVERITT. My name is Dee Everitt. I am president of the Association for Retarded Citizens of the United States, and I also—just by coincidence—come from Nebraska, Lincoln, NE, as does Pat Crawford. We have known each other a long, long time. We have been on opposite sides of the fence many times, but we are still friends.

The ARC–U.S. is a national organization of volunteers—parents, educators, professionals in the field of mental retardations, self advocates, and others. The ARC has been in existence for 35 years. Currently, our membership consists of approximately 200,000 individual members, over half of whom are parents of children with mental retardation. We are the largest organization in this country representing and promoting the rights of retarded people and their families.

As the president of the ARC–U.S. and as a parent of a daughter who is multiply handicapped, I would like to thank you for this opportunity to express the opinions of the ARC–U.S.

Over the past 10 months as the president of the ARC–U.S. I have received many, many letters. I became president in November at the beginning of the introduction of Senate bill 2053. I asked for input by all of our communications systems within the ARC, and I have read each and every letter that I have received—and, believe me, at one point there were 150 a week coming to my home.

I too have a daughter who is multiply handicapped—she has cerebral palsy and she has chronic epilepsy. My daughter lived in an ICF-MR for 3 years in her teen years. She has lived in our home and participated in the community for the past 15 years. I do have an understanding of why people place individuals with disabilities out of the home. I have shared the thoughts and suggestions received by our mail. I have shared this with our governmental affairs staff, our governmental affairs committee, and as a result we have shared these changes that we support with Senator Chafee and his staff.

We recently adopted a new position paper—we adopted several position papers, and one dealt with residential services. This position is directed toward phasing out of large institutions. We did not set a target date within this position paper, because we feel that large institutions are waning as an inevitable consequence of many things that are now happening. The future for people with mental retardation is toward the community and smaller settings.

We are now in a new age in the field of mental retardation. Parents with young children, even the most severely handicapped, are keeping their kids at home. Because of the passage of Public Law 94-142, the Education of All Handicapped Children Act, that is now an option for parents. Most parents are keeping their children at home and receiving care and training through the public school system.

The word "institution" I believe has been practically erased from their vocabulary. When I talk to young parents, they do not consider this an option.

I think we as an organization need to be responsive to these young parents and to their needs, and to look toward the future. I think it is time to let go of old models and embrace the new trend. I think Senate bill 2053 puts the responsibility of the Federal Government in concert with what many States are now doing. When you come forth with your new modified version of this bill, you will be truly responsive to the needs of persons with disabilities, even those with the most severe handicaps.

It is time the Federal Government gets in step with the new age in the field of mental retardation. This legislation will put into place in every State and community a system of stable but not static community services to support people with mental retardation. Federal funding must reinforce the State intentions in this direction.

The movement of people is well underway—about the same proportion of the total population is now provided with out-of-home care that 20 years ago was provided in large institutions. In other words, the ICF-MR beds are going down, according to a study that was done in 1982 entitled, "Report on Availability of Group Homes" for persons with MR in the United States. What I found interesting was that in 1982, 10,660 of the ICF-MR beds were within 1,100 facilities for 15 or fewer residents, and one-sixth of those were in Minnesota.

In short, a movement is underway. However, there is a lack of cohesion because States have been so dependent on Federal incentives and requirements, most of which is at cross purposes to the growing trend for community services. Many of the services needed by severely handicapped persons with MR are now listed among authorized medicaid services. That seems like an unreasonable choice for families who would rather keep their children at home or in the community.

I truly understand that change is not easy. This is a traumatic time for families, both those who want their individual to stay in an institution but also for those of us who want our individuals to live in the community. My daughter desperately needs a placement in a community facility. In Nebraska we have a large waiting list, and it simply is not possible because of a lack of funding.

I think I would like to close with a quote from a letter by Thomas Jefferson to a friend:

> I am not an advocate for frequent changes in the laws and constitutions, but laws and institutions must go hand in hand with the progress of the human mind. As that becomes more developed, more enlightened, as new discoveries are made, new truths discovered, and manners and opinions change with the change of circumstances, institutions must also advance to keep pace with the times.

I think that is what this legislation is all about—keeping pace with the times.

Senator DURENBERGER. Thank you very much.

[Ms. Everitt's written testimony follows:]

TESTIMONY

ON

COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

S. 2053

Respectfully Submitted

BY

Association for Retarded Citizens-U.S.

Witness:

Dee Everitt
President, ARC-U.S.

Monday, August 13, 1984
Minneapolis, Minnesota

The Association for Retarded Citizens-U.S. is a national organization of volunteers - parents, educators, professionals in the field of mental retardation, self-advocates and others. The ARC has been in existence for 35 years. Currently, our membership consists of approximately 200,000 individual members, over half of whom are parents of retarded children. We are the largest organization in this country representing and promoting the rights of persons with mental retardation and their families. As President of the ARC-U.S. and as the parent of a daughter who is severely retarded, I want to thank you for this opportunity to express the views of the ARC.

We are in a new age in the field of mental retardation. Parents with young disabled children no longer consider sending their child away to receive care, training and education. Indeed, the passage of Public Law 94-142, the Education for All Handicapped Children Act, and the availability of educational and certain other services within community settings have practically erased the word "institution" from the vocabulary of these parents. The use of institutions is not, and will never be, a desired option for them.

With families keeping their disabled children at home, there is now a growing demand for sophisticated, stable services systems within our communities. New experiences, new knowledge have created very different expectations from those of the past. It is time to let go of the old models and ideas and embrace the new ones. And it is the responsibility of the federal government to respond to these new experiences and this new knowledge and promote better services, better practices and better lives for our nation's mentally retarded and other disabled citizens. Your presence here today indicates the depth of your understanding of the situation in which disabled individuals and their families find themselves. I must commend you for holding this field hearing and thank you for your concern, openness and willingness to listen, and then to act.

Mental retardation is a life-long handicapping condition. Many retarded people continue to reside in large institutions where services are often primarily custodial in nature. The Association for Retarded Citizens believes that custodial care is a waste of human resources as well as dollars. We believe it is in the public interest to develop and maintain in every state and community a stable, but not static, system of community services which disabled persons may tap as needed to help them learn and maintain the skills to be as independent as possible.

Although the ARC has formally adopted a policy of working toward the eventual phase-out of institutions, we have not yet set a target date because we see the waning of institutions as a likely, inevitable consequence of our more immediate goals which are: 1) to implement community services which encourage and assist families to maintain their children in their home by alleviating the extra financial, emotional and practical burdens to which families may be subject; and 2) to establish arrays of family and community living arrangements and services which support the developmental and social needs of individuals with disabilities, and enable them to experience a life style that is as close to normal as possible.

Movement toward expanded home and community-based services and away from the use of institutions is already well underway. The census of public institutions for retarded people peaked in 1968. What is less well known is that the number of certified beds in Intermediate Care Facilities for the Mentally Retarded has also peaked. The 1981 total of approximately 196 thousand declined to about 132 thousand in 1982. The public component was 106 thousand in 1982 and is falling. In 1982 10,660 of these ICF/MR beds were in 1,157 facilities for 15 or fewer residents. You may be interested to know that one-fifth of all these people were in Minnesota. [Janicki, M.P., Mayeda, T., Epple, W.A.; "A Report on the Availability of Group Homes for Persons with Mental Retardation in the United States," November, 1982.]

Another figure that is interesting is that twenty-eight institutions have closed or been scheduled for closing in the last four years. [Braddock, D., Weller, T.; "The Closure of the Dixon Developmental Center: A Study of the Implementation and Consequences of a Public Policy," March, 1984.] During the same time period there has been an increase in state funds allocated to home and community services as well as the enactment of the Medicaid waiver program for such services.

In short, a movement is underway. However, this movement is somewhat erratic and lacks cohesion because states have been so dependent on federal incentives and requirements, most of which are at cross purposes to the growing trend for home and community services.

It is time for the federal government to get in step with the new age in the field of mental retardation. There is a new generation of families who have no use for institutions, there is an older generation who still have their adult disabled children at home, often without needed services, and there are those in institutions who need to be returned to our communities. S. 2053, the Community and Family Living Amendments of 1983, would eliminate the current biases for institutional care under the Medicaid program and support those services and programs for severely disabled people which are consistent with the new policies in the disability field which have emerged over the past two decades.

As you have acknowledged, Senator Chafee, S. 2053 is not perfect as currently written. The ARC has studied each and every provision of the bill, listened to the concerns expressed by those who oppose the bill in its current form and developed several modifications which we recommend be incorporated into the legislation. Each of our proposals is described in Attachment 1. While there is not time today to discuss in detail our suggested changes, let me point out one very important suggestion which directly responds to input from ARC members and to testimony given on February 27 at the hearing held by the Senate Subcommittee on Health. This particular suggestion takes into consideration the political realities in Congress as well as the views of those concerned about the total withdrawal of federal Medicaid funds from institutions as called for in S. 2053.

As introduced, S. 2053 requires a 100 percent withdrawal of the federal share of Medicaid money from large institutions within fixed periods of time, 10 years for some institutions, 15 for others. The federal funds would be withdrawn from large institutional facilities and become available for community-based services. Under the ARC modification, 85 percent, rather than 100 percent, of the federal funds would be withdrawn from the large institutions. The ARC revision clearly mandates that community services be included in each state's Medicaid plan.

In addition, this percentage phase out is combined with a plan to provide financial incentives for community placement. The incentive would reduce federal matching dollars in the institution while maintaining the federal match for community-based services. For example, if state X currently has a 50:50 federal-state match, the percentage of the federal match for institutions would decrease from 50 percent over a given period of time. Conversely, the 50 percent match for community services will remain the same. Thus, it would be increasingly more attractive for states to fund community services.. An ARC proposal regarding the percentage and time schedule is nearing completion and will be shared with you in the very near future.

Finally, the Secretary of Health and Human Services would be required to periodically assess the progress of the states in accomplishing the national goal of providing community-based services. The Secretary also would be required to make a comprehensive report to Congress, two years before the end of the 10-year period, concerning the states' progress. It is hoped that the Secretary's report will trigger Congressional hearings on the state of the art of community and other services in order to determine how the Medicaid funds should be used in accomplishing the national goal of community-based services for all people with mental retardation.

Certainly, I and other ARC volunteers and staff are available and ready to meet with you and/or your staff to discuss in greater depth the ARC proposals.

Under S. 2053 funds now used for care in institutions will be made available for community services. It is anticipated that many of those Medicaid certified facilities which cater primarily to eligible severely disabled persons will (1) become smaller, (2) close, or (3) be converted to other uses; the extent and scheduling of such a phase down or out and the sizes, types and locations of facilities, if any, to be maintained will be determined by state planning and priorities. States will continue at all times to be free to fund people and settings with state dollars and/or dollars available from other federal sources as appropriate. Providing states such decision making authority and flexibility allows them to respond to the specific situation and circumstances within the state and should result in the smoothest transition possible.

The ARC strongly supports those provisions of S. 2053 which require individual program plans and community services plans; the participation of clients, parents, guardians and others, as appropriate, in the interdisciplinary teams; the appeal procedures for clients, parents and others; the requirement for individual case management; the size limitation of not more than three times the average family household size within the particular community; and the accreditation of programs.

The ARC looks forward to working with Congress to refine and improve S. 2053 and to its early enactment. Again, I commend you for holding this field hearing and would like to close with the following quote from a letter by Thomas Jefferson to a friend:

> I am not an advocate for frequent changes in laws and constitutions, but laws and institutions must go hand in hand with the progress of the human mind. As that becomes more developed, more enlightened, as new discoveries are made, new truths discovered and manners and opinions change, with the change of circumstances, institutions must advance also to keep pace with the times.

That is what S. 2053 is about -- keeping pace with the times.

ARC-U.S. RECOMMENDS

CHANGES TO S.2053

"COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983"

April 17, 1984

On November 4, 1983, Senator John Chafee introduced S. 2053, the "Community and Family Living Amendments of 1983." The Association for Retarded Citizens of the United States helped with the drafting of the bill and strongly supports its intent. Since that time the ARC, as well as Senator Chafee, has sought input from around the country in order to improve the provisions in S. 2053. A hearing was held on February 27 before the Senate Subcommittee on Health. ARC President Dee Everitt has continued to request that ARCers concerned about S.2053 communicate to her their suggestions for change.

On March 31 and April 1, 1984, the ARC's national Governmental Affairs Committee met to decide what changes to S. 2053 should be recommended to Senator Chafee at this time based on the information provided in testimony at the hearing and in response to President Everitt's appeals for input from all those concerned. Mrs. Everitt has received many letters relative to S. 2053 and is extremely pleased with the constructive suggestions they contain.

President Everitt participated during the entire two day meeting of the Governmental Affairs Committee. The attached document describes each of the recommendations the ARC has endorsed and provides some explanation of these recommendations. A similar document has been shared with Senator Chafee. Final decisions on how best to modify S. 2053 probably will not be made for several weeks or months. Senator Chafee and the ARC are continuing to solicit input so that S. 2053 can be modified in the most beneficial manner for the mentally retarded and other disabled individuals affected by the bill.

ARC-U.S. RECOMMENDS

CHANGES TO S.2053

"COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983"

Recommendation	Explanation
1. Partial phase-out	
Require an 85 percent, rather than 100 percent, withdrawal of Federal Medicaid funds from institutions.	The 85 percent withdrawal would occur over the 10-15 year time line contained in S. 2053, and would be based on the total amount of Federal Medicaid funds flowing into institutions in the state on a specific date (as yet unspecified). (Specific examples describing the effect of the proposed changes on a state's Federal Medicaid funds will be developed and available in the near future.)
Provide for a cost-of-living adjustment relative to the 15 percent of Federal Medicaid funds allowed for institutional care at the end of the 10-15 year time line.	The adjustment for inflation will mean that states have 15 percent in real dollars still available for institutional care at the end of the 10-15 years. Details on this adjustment have not been worked out yet.
Require the Secretary of the Department of Health and Human Services to periodically assess the progress of the states in accomplishing the national goal of providing community-based services. The Secretary would be required to make a comprehensive report to Congress two years before the end of the 10 year period concerning the states' progress.	It is intended that the Secretary's report to Congress will trigger Congressional hearings on the state of the art of community and other services in order to further determine how Medicaid funds should be used in accomplishing the national goal of community-based services for all people with mental retardation as well as other disabled populations.
	A major advantage of the recommendations at left is that by retaining some amount of funds in institutions there is a strong, direct basis for enforcement of federal standards for such environments.

Partial phase-out (Cont'd)

Recommendation	Explanation
	The proposed 85% reduction is consistent with the Position Statement on Residential Services adopted by the ARC delegate body at its annual convention in November, 1983, and with the ARC Goals and Objectives adopted by the Board of Directors. It responds to input from ARC members, as requested by President Everitt, and to testimony given on February 27 to the subcommittee of the Senate Finance Committee. It takes into consideration the political realities in Congress and the views of developmental disabilities professional and advocacy organizations whose support of S. 2053 is important to its passage. It is important to recognize that the goal of phasing out large institutions requires first and subsequent steps; under present circumstances, the ARC's proposed modification enhances that goal. As stated above, the modification is based on practical and political reasons. The ARC does not believe that there is any segment of the mentally retarded population that needs institutional care on a permanent basis. The Committee is convinced that this modification is consistent with the policy direction set by the ARC/USA. Accordingly the Committee foresees that it will not initiate other changes in the withdrawal provisions.
2. Financial incentives for community services Eliminate the provision in S. 2053 which provides a 5 percent higher Federal match for home and community services to persons who were institutionalized for the first five years following their return to the community. Add a provision which would reduce the Federal matching rate for institutional care while maintaining the Federal match for home and community-based services.	The proposed modification will provide a more meaningful fiscal incentive for states to plan for and provide family home and community services, and avoid placing undue emphasis on services for institutionalized persons returning to the community. Many fear that S. 2053, as currently written, emphasizes services for persons leaving institutions at the expense of those already in the community, and that lengthy delays will ensue for those living in the community and in need of services, including those needing to leave home.

Financial incentives for community services (Cont'd)

Recommendation	Explanation
	Under the proposed change if state X currently has a 50:50 Federal-state match, the percentage of the Federal match for institutional care would decrease from 50 percent over a given period of time. Conversely, the 50 percent match for community services will remain the same. Thus, it will be increasingly more attractive for states to fund family home and community services. The percentage decreases and time schedule have not yet been determined.
3. Temporary institutionalization Alter the language of S. 2053 so that the provision for two year temporary institutionalization not include any stay in an institution which occurs prior to the 10-15 year withdrawal of 85 percent of the Federal Medicaid funds from institutions.	This change will provide more options and flexibility for the use of institutions following the withdrawal of 85 percent of the Federal Medicaid funds from institutions. Since 15 percent of the Federal Medicaid funds will remain available for institutional care the provision at left will only be relevant when the persons to be institutionalized trigger Federal Medicaid funding in excess of the 15 percent.
4. Eligible population Define the eligible population as those severely disabled individuals who have a disability as defined in Section 223 of the Social Security Act which began before the age 50, except for individuals between the ages of 21 and 65 who suffer primarily from a mental disease. Provide that any children or youth who are under the age of 21 when S. 2053 is enacted and who have a primary diagnosis of mental illness, retain their eligibility for family home and community services as they grow older.	Using the definition of the developmentally disabled with a higher age of onset has proven too confusing. The definition at left is based on the current definition of disability contained in the Social Security Act and will ensure that the definition of disability in S. 2053 is consistent with that used today to determine eligibility for Supplemental Security Income and Medicaid benefits. Simplifying the definition in this way makes it clearer that to be eligible for Medicaid, and consequently S. 2053, one must usually be eligible for Supplemental Security Income. Allowing mentally ill children who are eligible for services under S. 2053 to retain their eligibility as they grow

Eligible population (Cont'd)

Recommendation	Explanation
	older will mean these children will not be faced with the loss of appropriate services at age 21. By allowing mentally ill children and youth to continue eligibility into their adult years S. 2053 will be programmatically more appropriate for this population.
5. Options for those over 65 Alter language to allow either skilled nursing facility, intermediate care facility (not intermediate care facilities for the mentally retarded) or family home and community-based services for severely disabled persons over 65 years of age, regardless of their age at the onset of their disability.	Because public policy for elderly disabled persons is not as certain as that for the non-elderly disabled, because the trend in services for this population appears to be in the same general direction as that called for in S. 2053, and because many persons feel that nursing homes are appropriate and "normal" for some elderly disabled persons, a recommendation is being made to allow either institutional (including nursing homes) or family home and community services for disabled persons over 65 years of age. It is intended that the Secretary's comprehensive report to Congress (see recommendation 1 above) will clearly address best services practices for this population as a basis for future decisions regarding the use of Federal Medicaid funds to serve those elderly persons with severe disabilities.
6. Identification of eligible persons in nursing homes Add specific language requiring states in their implementation agreements to undertake (i.e. make a committment) to identify within one year and annually thereafter eligible severely disabled individuals who are living in skilled nursing facilities, intermediate care facilities, and board and care facilities having 16 or more beds and in which a significant number of recipients of Supplemental Security Income are likely to reside.	To strengthen the protections of severely disabled persons currently residing inappropriately in nursing homes states must be required to clearly commit to the development of a process for identifying eligible severely disabled individuals in SNFs, ICFs and board and care homes since such a process does not currently exist in many states and is essential for appropriate planning for the future.

Recommendations	Explanation
7. Protecting existing services Add language stating that the amounts expended for community and family support services shall be in addition to any forms of medical assistance for which the individual would otherwise be eligible under the state's Medicaid program, except for Skilled Nursing Facilities, Intermediate Care Facilities, and ICF/MR services.	The recommended language will state explicitly that the services eligible for Medicaid reimbursement under S. 2053 would in no way jeopardize an individual's entitlement to other services under the state's Medicaid plan. For example, basic Medicaid services such as hospitalization and special services such as in-patient psychiatric care would clearly be retained as eligible Medicaid services under S. 2053.
8. Mandating and itemizing services Require states to include in their Medicaid State plans an array of community and family support services for any severely disabled individuals who are entitled to medical assistance under the plan and who live in family homes or community living facilities. Language would be added requiring the array of services, when combined with other medical assistance available under the plan, to be sufficient in quality, extent and scope to assure the health, safety and effective habilitation or rehabilitation of such individuals. This array of services would be selected from the following list: - case management services; - periodic interdisciplinary diagnostic and assessment services; - personal assistance or attendant care; - domestic assistance necessitated by the individual s disability; - services to enable the individual to improve or maintain functional capacities; - prostheses, assistive devices, supplies and appliances; - adaptation of equipment or vehicles, or of housing or other space to be used by an eligible severely disabled individual;	To ensure that states provide appropriate family home and community services under S. 2053, such services should be itemized and mandated to the greatest extent possible. As appropriate under Medicaid law the provision to the left requires states to offer family home and community based services and allows states, for the most part, to select an array of services from those listed. Several specific services were listed in response to input from concerned individuals. For example, supplies (meaning expenses incurred for such things as diapers, special diets, special play equipment, special clothing, tape, gauze, cushions, straps, ointments etc. that exceed those required for a normal person of the same age); adaption of equipment, vehicles or housing; personal guidance, supervision, counseling, representation or advocacy; special transportation services; specialized training for families or caregivers and preventive services.

Mandating and itemizing services (Cont'd)

Recommendation

- comprehensive outpatient rehabilitation facility services;
- personal guidance, supervision, counseling, representation or advocacy;
- adult day programs;
- services (other than board or lodging or basic foster care) provided to any severely disabled individual by a family with whom such individual is living;
- support services to families or care-givers including (i) specialized training and (ii) respite care in or out of home or usual residence;
- special transportation services;
- homemaker/home health services;
- chore services;
- crisis intervention;
- protective services;
- specialized vocational and occupational services that will enhance the independence, productivity, and community integration of a severely disabled individual, including employment training, support necessary to maintain the employment of such individual, and other training and therapeutic activities specified in the written plan of habilitation or rehabilitation developed with respect to such an individual;
- appropriate preventive services to decrease the needs of eligible individuals for future services;
- any other services identified by the State and approved by the Secretary as conforming with the purposes of this section; and
- amounts expended by any state agency or provider of services under this section to administer the provision of community and family support services shall be treated as administrative expenses of such plan.

Recommendation	Explanation
Room and Board To permit no payment for room and board other than room and board provided for a period of not more than six consecutive weeks as an integral but subordinate part of a service funded under S. 2053, except that auxiliary payments may be made to cover extraordinary costs of food or housing attributable to the disabling condition(s) of a particular individual or individuals.	Concern has been expressed that open ended payments for room and board would foster "facility" or packaged models of care rather than individualized services. Other concerns were the potential confusion about the use of Supplemental Security Income payments (which are specifically intended for room and board) in conjunction with Medicaid payments for room and board, the possible duplication of the two funding sources, and the potential high cost of the room and board provision as currently written. The suggested change at left allows for room and board payments for respite care or emergency situations and as payments to supplement other funding for room and board, such as SSI, when necessary due to extraordinary or unusual food or housing expenses required because of the disabled person'(s) condition(s). For example, costs in excess of the SSI payment which are due to special building or life safety code requirements for structures housing disabled people might justify a supplementary payment from Medicaid under S. 2053.
10. Mandated protective services Add language to require states to assure, as needed, the timely availability of protective services. Require that these protective services as well as the mandated case management services be available to any severely disabled individual, even if his income or resources exceed the criteria set for eligibility under S. 2053.	Due to the recent Baby Doe situations it is increasingly important to establish state responsibility for a meaningful protective services system for severely disabled people, without regard to income or other assets. In addition, individualized case management services continue to be viewed as the core for responsive, effective services in a community-based system of care and should be available to all persons determined to be severely disabled.

Recommendation	Explanation
11. Expanding grandfathering provision	
Expand the grandfathering provision to include all exisiting facilities with up to 15 disabled residents (does not include staff living and/or working at the facility). In addition, add language that allows existing facilities with more than 15 residents which decrease their size to 15 or fewer residents at some time following the enactment of S. 2053, to have their residents (if otherwise eligible) receive services reimbursable under S. 2053.	As written S. 2053 only grandfathers facilities with up to 15 persons if they are certified as an intermediate care facility for the mentally retarded. It is not sound public policy, to allow these facilities to continue funding under Medicaid while disallowing Medicaid reimbursement for services for individuals in other existing facilities of similar size simply because, at the time of enactment, they are not certifie ICFs/MR. In the same vein, it is appropriate to add language extending Medicaid reimbursement for S. 2053 services for severely disabled individuals in other existing facilities once these facilities reduce their resident population to 15 or fewer persons.
12. Training as a reimbursable item	
Add language modifying current Medicaid law applicable to reimbursement for training (currently a 75:25 matching rate) to include the training of personnel skilled in the delivery of community and family support services needed by persons with severe disabilities, whether employed by a public agency or any agency under contract to the state to provide services under S. 2053. Further, states would be required in their implementation agreements to include provisions to ensure that training is made available to natural, adoptive and foster parents of severely disabled persons as well as staff of community living facilities.	S. 2053 requires states to provide training but does not allow for Medicaid reimbursement of such training. It is evident that training is a critical factor in assuring quality services and has been a significant problem in many community service systems. Many advocates for S. 2053 have expressed a strong concern for the lack of funding for appropriate training including the training of natural, adoptive and foster parents.
13. Adequate fee levels	
Add language to modify current law to require, to the greatest extent feasible, that states set fee levels, i.e. rates of reimbursement, for community and family support services that are reasonable and adequate to assure the provision of care and services which conform with applicable state and federal laws, regulations	A major problem in providing quality community services under the Medicaid program is that states often set fee levels too low to ensure such quality. While it would be inappropriate to mandate fee levels on a national basis the language at left will require, to the greatest extent possible, adequate rates of reimbursement for family home and community services.

Adequate fee levels (Cont'd)

Recommendation	Explanation
and applicable quality and safety standards; to assure that severely disabled individuals eligible for medical assistance have reasonable access (taking into account geographic location and reasonable travel time for family and friends) to community and family support services of adequate quality; and to enlist enough providers so that these services are available to severely disabled recipients at least to the extent that services under the plan are available to the general population.	
14. Equating income eligibility criteria	
Add language to equate the income eligibility criteria established under Medicaid for institutional and community services. Such language may read: "if the state establishes a separate income standard for individuals who are in any medical institution, the state must establish the same separate income standard for all severely disabled individuals."	Under current Medicaid law states may set a separate income standard for persons in institutional settings. Such a standard may allow an individual to have an income up to three times the federal Supplemental Security Income amount. This option is generally not allowed for disabled persons seeking Medicaid reimbursement for community-based services. The additional language at left will equate the income eligibility criteria.
15. Medicare gap	
Add language stating that whenever an individual is receiving benefits under Title II of the Social Security Act as an adult disabled during childhood (ADC) and as a consequence of such Social Security income is found ineligible for SSI benefits, such individual shall be deemed to be eligible for services provided under S. 2053, ie. treated as if he were an SSI recipient.	Concern has been expressed that persons whose benefits under the ADC program are too high to qualify them for SSI and consequently for Medicaid must wait two years in order to receive benefits under the Medicare program. The language on the left deems such persons eligible for S. 2053 services. However, the language goes further than covering services during the two year gap and allows ADC individuals to continue their eligibility for S. 2053 services even after they become eligible for Medicare. It would not be good public policy to provide services under S. 2053 only to withdraw eligibility two years later. The fact is the Medicare program does not reimburse in any meaningful way services like those in S. 2053. It is important to note that the suggested language does not cover ADC persons who have income and resources other than ADC benefits which would cause them to be ineligible for SSI.

Recommendation	Explanation
15. Maintenance of effort Add language prohibiting states from suspending, reducing, discontinuing or terminating the medical assistance provided under their state plan because of any financial constraints created by the reductions called for in S. 2053.	In response to concern about the states' maintenance of effort under S. 2053 the language at left was developed. However, it does not require that the total amount of state Medicaid matching funds currently used to provide services for retarded and other severely disabled persons, both insitutional and community-based, be maintained, i.e. as services shift to the community the states are not mandated to maintain the same total amount of dollars for services to disabled people. Legal counsel suggests that such language would be inappropriate under Medicaid law and that the language to the left is more appropriate.
.7. Fair employment standards for employees of private programs Add language requiring states in their implementation agreements to assure the application of fair employment standards to workers in private programs and facilities offering care and services as described in S. 2053.	There is a great deal of concern in the field of mental retardation about the difference in salaries paid to public employees versus workers in private programs or facilities. The low wages in private programs are sometimes cited as a factor in high staff turnover and consequently, substandard care. The suggested language at left is aimed at helping alleviate this problem by requiring states to assure the application of fair employment standards to such employees. While higher salaries will increase the cost of community services, salaries are only one factor (albeit an important factor) contributing to the generally more expensive institutional environments. For example, the division of labor, ie. specialized jobs, required in institutions is another factor contributing to institutional costs.

Recommendation	Explanation
18. Service requirements for community living facilities Add language stating that community living facilities, in providing living arrangements, care and services to severely disabled individuals, must cooperate with other providers and with appropriate case managers in implementing a written plan of habilitation or rehabilitation for each individual.	Critics of S. 2053 have stated that as written the bill implies that community living facilities must themselves provide or be the focus of responsibility for all services to their residents. The suggested language on the left will clarify that such facilities must cooperate with other providers and the individual's case manager to assure the provision of appropriate services.
19. Private enforcement Alter the language of the private enforcement provision to read as follows: SEC. 5. (a)(1). Any person injured or adversely affected or aggrieved by a violation of this Act by a state agency administering a State Plan approved under section 1902(b) of the Social Security Act may bring an action to enjoin such violation. (2) An Action brought under paragraph (1) shall be brought in the appropriate district court of the United States within the state in which such State Plan is in operation. (3) Such party may elect, by so stating in the complaint filed at the commencement of such action, to recover reasonable attorney's fees and costs from the defendant in the event that such party prevails. (b)(1) Upon filing a lawsuit under subsection (a), the complainant shall give notice by registered mail to the Secretary of Health and Human Services, the Attorney General of the United States, and the state agency administering the State Plan alleged to be in violation of this Act.	After obtaining legal advice it was felt that the private enforcement language in S. 2053 could be significantly improved and clarified. New language is presented at left. This language specifically states that aggrieved persons may sue the state agency administering the state Medicaid plan (rather than the plan itself), and may file to recover reasonable attorney's fees as well as costs. The fact that the Secretary approved the particular plan in question shall not bar action against the state agency. Previous language stating that "no action could be brought if, at the time the complaint is filed, the same alleged violation by the same state agency administering the plan is the subject of a pending action in any court of the U.S." was deleted because it was unnecessary.

Private enforcement (Cont'd)

Recommendation	Explanation
(2) The notice required under paragraph (1) shall state the nature of the alleged violation, the court in which such action will be brought, and whether or not attorney's fees and costs are being demanded in the event the plaintiff prevails. (c) The approval of the State Plan, with reference to the provisions of this Act, by the Secretary shall not be a bar to the bringing of an action under paragraph (1) nor shall it constitute a defense to any such action.	

20. Timelines for implementation

Require states to provide some family home and community services in the first year following enactment of S. 2053. (Federal Medicaid matching dollars would be available for such services.) Allow states two years following enactment to complete their implementation agreements. The 10-15 year time period for the withdrawal of 85 percent of the Federal Medicaid funds from institutions would not begin until completion of the implementation agreements.	To ensure an orderly, well-planned transition from institutional to family home and community services, states should be given two years to complete their implementation agreements. This allows time for the Federal government to develop and publish regulations implementing S. 2053, gives states time to complete the individual community services plans for institutionalized persons and to identify persons inappropriately placed in nursing homes and general ICFs. All of this information is necessary for states to develop a meaningful, data based implementation agreement. While it is important to allow states sufficient time to complete their implementation agreements, it is equally important that states be required to begin providing appropriate home and community services in the first year following enactment so that the actual provision of such services is not delayed. Delaying the beginning of the 10-15 year time line for the withdrawal of 85 percent of the Federal Medicaid funds from institutions until the third year following enactment (after completion of states' implementation agreements) in essence provides two additional years for the withdrawal to take place

Timelines for implementation (Cont'd)

Recommendation	Explanation
	i.e., in reality, the 10 years would become 12 and the 15 would become 17.
21. Standards for non-certified institutional beds Eliminate the provision in S. 2053 which would require that all institutions currently not certified as Intermediate Care Facilities for the Mentally Retarded comply with the federal standards for the ICF/MR program.	Under current Medicaid law states may chose whether or not to have each of their institutions certified as ICF/MR. Requiring states to bring all institutions into compliance with the Federal standards would mean a significant influx of Medicaid dollars into institutional environments. Such a requirement is not consistent with and is, in fact, at odds with the intent of S. 2053. Not requiring massive expenditures, primarily for capital improvements, in institutions does not mean that institutionalized persons should have less than the highest quality of services.
22. Client and advocate involvement in decision-making Clarify language throughout S. 2053 to ensure the involvement of the disabled individual himself and, as appropriate, his advocate (in addition to his spouse, parent, guardian or appropriate family member) in all living arrangement and services decisions (and corresponding appeal procedures) for the disabled person.	It is important to make it clear that the disabled individual and, as appropriate, his advocate must be involved in all decisions (and corresponding appeal procedures) relative to the persons' living arrangements and services requirements.
23. Appeal procedure for persons in various community settings Add language requiring an opportunity for an appeal and fair hearing before an impartial hearing officer for any individual (or his spouse, parent, guardian, appropriate family member or advocate acting on his behalf) who believes himself to be inappropriately placed or who is denied an appropriate placement or service, or who is being scheduled for transfer from one community living arrangement to another otherwise than on his own initiative.	S. 2053 provides such an appeal procedure only for persons scheduled for transfer from an insitution to a community setting. It is equally important to have such an appeal process available to those living within the community.

Recommendation	Explanation
24. Deeming of resources for children Add language to allow states to provide S. 2053 services to disabled children who, except for resources deemed to them, would be eligible to receive Supplemental Security Income benefits.	Under the Supplemental Security Income program disabled children are often found ineligible solely due to family resources which are deemed to be available to them. Denial or loss of SSI usually results in ineligibility for Medicaid. The language at left would allow states to choose to provide such children with S. 2053 services reimbursable under Medicaid.

OTHER DECISIONS/ISSUES IDENTIFIED BY THE ARC

1. Start-up costs/capital construction - The Committee recognizes that such costs cannot be met under the Medicaid program. Other Federal and state programs which can provide start-up or capital construction monies were identified to be targeted for expansion. In addition, a recommendation will be made to Senator Chafee to require states to describe in their implementation agreements their plans for meeting such expenses.

2. Integration of S. 2053 language into existing law - The Committee endorsed the idea of integrating, to the greatest extent possible, the language of S. 2053 into existing law by using conforming amendments.

3. Clarifying audits, reviews, monitoring requirements - The Committee is further researching the most appropriate and effective audit, reviews and monitoring mechanisms to be utilized under S. 2053.

4. Intermediate size facilities - The Committee made no changes in the size requirements in S. 2053. It was felt that, at this time, there is insufficient data to justify any expansion of S. 2053 coverage for facilities with more than 15 residents. This major issue is still open for further consideration. Key national organizations (e.g. National Association of Private Residential Facilities for the Mentally Retarded) and individuals have been requested to provide specific data and recommendations.

5. Expanding consumer involvement - The Committee is supportive of an expansion of disabled persons' involvement, when appropriate, in their services program, e.g., the selection, hiring and training of attendants, and is further researching the most appropriate language to accomplish this expansion.

Senator DURENBERGER. Ms. Everitt, let me ask you a question about the position of ARC. Your testimony has three recommendations for modifications in S. 2053, but attached to your testimony is a set of additional recommendations, many of which seem to indicate a necessity or recommendation to us to expand the eligible population for these services, expand the scope of services, and I guess I am wondering whether or not ARC's position here on 2053 is conditioned on expanding the population eligible and the scope of services, and if you have any idea what that might cost.

Ms. EVERITT. Senator, these changes came about as the result of an opening up of comment which we have done throughout our organization. I tried to consolidate with our governmental affairs staff and committee those changes, and that's what this is a result of. This is in addition to our position on phasing out of institutions. But these were the things that people wrote to me and said they were concerned about. We tried to take the positive ones, the ones that we thought were most feasible to do, and we submitted those to Senator Chafee for his discretion.

Senator DURENBERGER. And those three are the 85 percent rather than the 100 percent on the penalties, the financial incentives of community placement, and then the periodic assessments?

Ms. EVERITT. Yes.

Senator DURENBERGER. All right, thank you.

John.

Senator CHAFEE. Thank you very much, Mr. Chairman.

First, I want to thank each of you for coming here today. You have come a distance.

Mr. Beer, you heard the Michigan testimony of Mr. Babcock. What do you think of that approach? In other words, it seems to me they use great care for those constituents that you represent.

Mr. BEER. Senator, thank you for asking about that. I found Mr. Babcock's comments interesting, and I would just preface my answer to your question by saying that I am not personally conversive with the Michigan experience, but have had contact with our union representatives in the State of Michigan concerning what has happened in Michigan over the past 2 to 4 years, which I believe is the period of time Mr. Babcock was referring to.

From the perspective of the organized union member represented by ASME in the State of Michigan, the experience has been I think somewhere between a mitigated and a controlled disaster—unmitigated and controlled disaster. And I say that not to disparage the approach, the technical approach taken by the State once that decision was made to move as massively and as rapidly as they did, because of some other things that I think intervened in Michigan. One of them was the state of the Michigan economy that during the heavy recession, depression, of that time I think fueled considerably the move toward rapid depopulation as a budgetary item. That is my own opinion of that.

In talking to Michigan and our international staff about the current status of things in Michigan—and, by the way, one of our own staff members has traveled to Michigan recently to view some of those facilities—we find that what we believed to be a replication of a problem that we think is significant in the changeover to the delivery services, and that is the staffing situation, is not as stable, certainly not as well remunerated, well paid, and that we believe in the long term is going to show itself in the quality and type of programming that will exist in Michigan.

I believe Mr. Babcock cited some statistics about the numbers of people who remained in mental health care as the result of the changeover. My thought in hearing that was, in the state of the Michigan economy I'm sure any employee would grab at almost any straw in that situation, and the State did extend itself to try to develop I think some options.

Senator CHAFEE. You visited Rhode Island, and there you saw a little different approach—namely, that our homes are still State run, State owned, or State rented. And in your testimony you seemed to laud that experience.

Mr. BEER. Senator Chafee, yes, I did. Again, I personally did not travel there but a number of our staff did. We had Dr. Robert Karl from Rhode Island out here. Their experience I think, for us—and I think also it should be for advocates for the retarded who are not union employees. I think they should take note of that system.

The transfer of well-trained motivated staff into community settings which are small, individualized, has taken place there. They have done it in a way that has over time, and I believe they have been at it for over 5 years, reduced the institutional population, reduced—according to Dr. Karl—the numbers of dollars spent on institutional care vis-a-vis community care, and has done it in a way that hasn't thrown out the human resource of the staff and created a situation of near structural unemployment.

So we are very high on that experience. We don't believe it can be replicated down to the crossing the last "t" and dotting the final "i" in Minnesota. Rhode Island is different from Minnesota. And the first thing that is brought up is the size of the State. But I think there are enough similarities that it demands some serious consideration. We hope we are going to be getting that in this State.

Senator CHAFEE. I will say, as you know the thrust of this legislation is to provide the best care for the individual. If there happens to be a bonus in savings, three cheers. But that's not the reason I advocated the legislation.

But it is amazing, the testimony that we've had, that it is less expensive to operate the community setting than the institutional.

Then, in your testimony and in Mr. Babcock's, you also suggested, "Well, but they have had to give wage increases in the community homes." I find that hard to say, because clearly they would have to give wage increases to the institution employees as well. So I don't think we can compare apples to oranges; it's got to be the expenses when they made the transfer, a year compared to the same year of community versus institution. It is not fair to take what the institution was and what the community is 5 years later in the increased costs.

One final question to Ms. Everitt.

You mentioned allowing 15 percent of the Federal medicaid funds to be used to fund an alternative method of care. What were you thinking about? What might that be?

Ms. EVERITT. We were suggesting that 15 percent of the Federal—then you would require an 85 percent rather than a 100-percent withdrawal of Federal medicaid from institutions.

Senator CHAFEE. So you might well have a residual population?

Ms. EVERITT. Yes, such as Mr. Babcock was talking about; they don't know how many of the medically fragile.

Senator CHAFEE. Also you remember what he said—he thought as you proceeded over the years and the technological developments improved, he could see a zero population.

Ms. EVERITT. I can see that. I see that happening in Nebraska now, in some instances.

Senator CHAFEE. All right. Well, thank you all very much, Ms. Crawford and Ms. Everitt, and Mr. Beer, for coming. We appreciate it.

Senator DURENBERGER. Thank you.

Our next panel consists of A.L. Napolitano, executive director, Bethesda Lutheran Home in Watertown, WI; Gerald Walsh, executive director of Mount Olivet Rolling Acres Residence on behalf of the Minnesota Network of Not for Profit Providers of Mental Retardation Services, Minneapolis; Jon Nelson, executive director, Christian Community Living Systems, Watertown, WI; and Lyn Rucker, executive director, region V, Mental Retardation Services, Lincoln, NE.

We might as well proceed in the order that you were introduced.

Again, I indicate that your full statements will be made part of the record, and you will be rewarded in some way by keeping your opening remarks within 5 minutes.

Mr. Napolitano.

STATEMENT BY A.L. NAPOLITANO, EXECUTIVE DIRECTOR, BETHESDA LUTHERAN HOME, WATERTOWN, WI

Mr. NAPOLITANO. My name is Alexander L. Napolitano. I am the executive director of the Bethesda Home, Watertown, WI. I wish to thank the committee for the opportunity to testify.

As the executive director of the Bethesda Lutheran Home, which has 80 years of experience in the nonprofit sector services to the retarded, we function both in the institutional setting and in the group home setting, and in the community at large. Therefore, we feel we have gained the experience over this period of time to be able to speak on behalf of objecting to 2053.

We feel that there will continue to be a need for the institutional services for those to serve the severely and profound, the medically fragile, and the behavorial. If we listen to the testimony of some of the previous people, when you began to pin them down, all slowly began to admit, "Well, there might be a residual—yeah, we think there may be some. Yes, we think it looks like there would be some people left." I cannot understand why one organization all of a sudden or one thrust has to eliminate something that has been working in private organizations and doing an excellent job for these past 80 years. All of a sudden there is only one way to do it. And in order to accomplish that, we must eliminate all the institutions, all that they stand for, and all that they have accomplished.

We have worked diligently. We moved 300 residents on our own. We have continued to move them. We are not looking for a Federal handout. We supply 50 percent of our own funds, to the tune of $7 million.

The funds that are received are entitlement funds to the residents themselves, not to the facility.

The other point that stresses us greatly is in the country that speaks for freedom we all of a sudden find ourselves that we are going to eliminate one of the treasured things, and that is the freedom of choice for the retarded person, for their families, and for their guardians.

Again, that concerns us. Why all of a sudden is there only one way of doing things? Why, when all there is that is available—and there is room for all of us to help—why can't we all help together? Why must we eliminate somebody to do what we purport to be the best thing?

Let's enforce the existing laws. I have been begging, I have been writing—I sent Senator Chafee a movie—I have been pleading for people to come and visit private facilities. Yet all we hear about is the bad facilities. They are in the paper. There is no mention made of the good facilities. And I find that ironic, that all of a sudden "there are no good ones." Eighty years means nothing. We serve 2,600 people. Where were all these people who now profess to have all the answers? Where were they 20 years ago? Let's enforce the present laws. And if a facility can't measure up, let's close them out; but let's leave the ones that are doing an excellent job stand. Let them stand on their merits.

I make an open invitation to anyone here: You can come day or night, and if you don't have the money we'll scrape it up to get you there. But take a look at some of these facilities. Let's utilize the waiver. Let's make it permanent. Let's make it work for us. It is already showing that it is working. Let's utilize the ICF-MR and realize it's not a kind word to say, but let's utilize it for the 15 beds or less. Now, there has been very little advantage taken of that. Everybody talks of more than 15—of 100, 200, 300. Nobody is making mention of the 15 beds or less, which is a viable option.

These programs also have an advantage in that they require some sanity in planning and they require some cost-effectiveness.

The arguments on cost can go back and forth, and I think one of the problems I have seen in this bill is that it deals greatly in generalities. We are talking about a whole Nation We are talking about going to New York City and putting in scattered sites for 10 million people. Now, you know, in one block you've got hundreds of thousands of people. We had this when we had the captionate areas in mental health. What about Montana? What about New Mexico, where the populations are sparse, as was pointed out in the Dakotas. I guess what we are telling those people is, "No, you can't bring your services under one roof; you must find some way to scatter them out, even though there aren't enough staff or there aren't enough resources to carry them."

In conclusion, big is not bad, and small is not always best. And I think we can find proof of that anywhere we want to find it. It all boils down to the need for excellence, to the need for commitment, to love, to the philosophy of the facility giving the care, not to size.

Once again, one of the founding things here that concerns me the most is that we maintain freedom of choice.

Thank you.

Senator DURENBERGER. Thank you very much.

Mr. Walsh.

[Mr. Napolitano's written testimony follows:]

STATEMENT OF ALEXANDER L. NAPOLITANO
ON BEHALF OF BETHESDA LUTHERAN HOME
WATERTOWN, WISCONSIN 53094
Regarding Proposed Amendments to S. 2053
THE COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983
Before the Health Subcommittee
of the Senate Finance Committee
August 13, 1984, at Minneapolis, Minnesota

As Executive Director of Bethesda Lutheran Home, 700 Hoffmann Drive, Watertown, Wisconsin 53094, I would like to thank the Subcommittee for this additional opportunity to comment on S. 2053 and some of the amendments which have been proposed by various professional and advocate organizations - and for the opportunity to offer the suggestions of our organization regarding better ways to meet the needs of retarded individuals.

I. BETHESDA'S EXPERIENCE

A. History: Since 1904, Bethesda Lutheran Home has served over 2,600 retarded children and adults, earning a nationwide reputation for excellence in the field. Currently we serve over 470 retarded individuals from 31 states and one foreign country on our main campus in Watertown, Wisconsin. We also operate 10 group homes in eight states and have three more under development, for a total of 103 licensed beds. Just this month, we have also acquired Faith Village in Kansas. This consists of three cottages of 15 beds each in Shawnee Mission and two 10-bed group homes in Olathe.

B. Services: Located on 475 acres along the scenic Rock River, our main campus includes dormitories, a vocational workshop, therapy rooms, an infirmary, detached small group homes, an educational center, a chapel, service buildings and extensive recreational facilities (gym, swimming pool, arts and crafts, ball diamonds, playgrounds, outdoor shelters, and a large wooded campground). Bethesda employs a staff of 600 people, including doctors, nurses, therapists (occupational, physical, speech, recreation and music), psychiatrists, psychologists, residential aides, chaplains, teachers, social workers, a pharmacist, medical technologist, librarians, and a volunteer coordinator (who works with the more than 5,000 volunteers who befriend, chaperone, assist and provide special entertainment for our residents, donating over 70,000 hours each year).

C. Goals: Through treatment and training programs, Bethesda strives to help retarded individuals develop their talents and abilities to their fullest potential, thereby enabling them whenever possible to live satisfying and productive lives in the community. A complementary goal is to instruct them in the Christian faith so that they can experience the joy of a Christian lifestyle.

In addition, we are concerned about the thousands of retarded persons in this country who do not have access to religious instruction in their local community, and for this reason we have developed an Outreach Program to prepare churchworkers for teaching retarded children and adults in local parishes. We are also developing a Christian Resource Center as well as a Diagnostic and Evaluation Center. We publish curriculum materials, which we make available free of charge or at cost. Some of these materials have been translated for use in other countries, and we currently are sponsoring a physical therapist who is treating handicapped students and training staff at the Lae

Special Education Center in Papua New Guinea.

II. POSITION REGARDING S. 2053

As stated in testimony submitted at the February 27, 1984, hearing on this bill, we believe that S. 2053 would disserve the interests of America's retarded citizens for the following reasons:

1. S. 2053 would have the effect of closing all institutions for mentally retarded persons, including private institutions such as Bethesda.

2. S. 2053 assumes, without basis, that institutional care is universally inferior to small group care for all retarded citizens.

3. S. 2053 incorrectly assumes that community placement is always the least restrictive alternative, even for severely and profoundly retarded people.

4. S. 2053 would make it much more difficult for retarded citizens to exercise their religious freedom.

5. S. 2053 assumes, without basis, that the cost of implementing group home care for retarded people would be less than institutional care.

6. S. 2053 does not take into account the failures nor prevent repetition of the abuses which have resulted from previous deinstitutionalization programs.

7. S. 2053 ignores the effect of deinstitutionalization on families of retarded persons, on staff members who care for retarded people, and on the community at large.

8. S. 2053 is not a necessary prerequisite to the development of group home care.

III. REACTION TO AMENDMENTS PROPOSED BY VARIOUS ADVOCATE GROUPS

A. <u>We agree with the following proposals</u>:

1. We agree that persons over age 65 should have access to Medicaid-funded nursing home care without any time limitation. When people become elderly, many disabilities occur which place

impossible demands upon families and require extensive nursing support. Living in the family home under these circumstances may be more restrictive, regardless of whether the person is retarded or of normal intelligence.

2. We agree that protective services and case management should be <u>available</u> to any disabled individual, regardless of income or other assets. If assets are sufficient, however, the individual should be expected to pay for these services. Some proposals call for <u>mandating</u> such services - here we would urge caution, lest families be totally deprived of input and influence.

3. We agree that the appeal process should definitely be available not only to those moving from an institution to a home in the community but also to those in the community who believe they are inappropriately placed.

4. We agree that Medicaid should be available to children living at home for services they require - IF and <u>only</u> IF the family cannot afford such services.

B. <u>We strongly disagree with the following proposals</u>:

1. We do NOT believe that Federal Medicaid funds for persons in institutions should be phased down to 15% of the amount allowed for institutional care at the end of the 10-year time line of S. 2053. While 15% is an improvement over the total phaseout concept of S. 2053, it is NOT acceptable.

If the goal of this bill truly is normalization and equality of opportunity for all retarded persons, then it must be remembered that:

a. People of normal intelligence do have the freedom to choose where they will live and receive education and training, including institutional types of settings. For instance, these choices often include boarding schools for young people and colleges (in all parts of the country, often with the aid of federal loans and assistance) for adults. People with physical problems can go to outstanding hospitals and clinics throughout the country, with care being funded through a variety of government aid and insurances. Should retarded persons have less choices?

b. An institution CAN be the least restrictive setting for severely and profoundly retarded persons, especially those with physical disabilities and specialized medical needs. A good institution provides greater concentration of services and benefits for less expenditure of time and money than a community setting. With continued objections to increased taxation, we must not eliminate the most efficient way of providing services.

c. Some medically fragile people may always need or be best served in an institution. For these people, the two-year limit would be grossly unfair. There are some disabling conditions which require around-the-clock nursing care. When such people are in a small group home, what happens when the scheduled nurse quits or becomes suddenly ill and no replacement is available? At Bethesda, individuals who are confined to bed are placed in carts and moved to other areas of the institution for treatment, training and recreation - a situation infinitely better than being confined to one room of a home in the community.

d. Others who may have greater freedom in an institution include those who are so low level that they have to be supervised constantly; some also need the routine and structure that only an institution can offer. Of even greater concern, though, are those who have behavioral disorders, psychotic tendencies or bad personal habits. They can be a danger to themselves and others - an impossible situation in a group home - and need the constant monitoring and safety which only an institution can provide.

e. Using the 10-year mark as the basis for continued funding at 15% or some other percentage does not take into consideration the shifting population of this country, especially the Sun Belt influx - nor the changes in the birth rate resulting from the cyclic baby booms, the next of which is predicted for the early 1990s.

2. We do NOT agree that private facilities should be required to meet the wage standards of public institutions. This would in effect take away the rights of private enterprise to determine salaries and job requirements. Private enterprise is basic to the American system and should not be limited by

additional laws of this type. Existing minimum wage laws are adequate.

At Bethesda, we hire an outside consulting firm which surveys salaries and benefits at hospitals and nursing homes in our region, and we seek to meet the average or higher. More than 50% of our employees have been with us for over five years. Last year we honored 10 employees who have served over 25 years here.

3. We do NOT agree that training of workers should be covered by the bill. Educational assistance in many forms presently is available to those who cannot afford education. Our field of employment should not expect something not offered to other industries.

4. We are further disturbed by the complexity of some of the proposed remedies for the problems which many have seen in S. 2053.

Some are so encompassing that they would make the bill a nightmare to administer. One example is the proposal to mandate adequate fee levels. Fees for services vary from state to state and region to region. Who determines what is adequate? And how? Competition, not government regulation, is the traditional American answer. To attempt to lure more health care professionals into service to retarded persons by raising the acceptable fees can only result in even higher costs in an already over-priced field.

Furthermore, the extension of a virtually unlimited, individualized array of services, as proposed by some advocates, could make the bill cost prohibitive.

IV. WHAT WE SUGGEST:

Needs of retarded people are as varied as there are people. How to meet those needs best is still the subject of great conjecture.

Many of the community experiments in serving severely and profoundly retarded children and adults have been performed under the most ideal situations. For example, a pioneering group home for severely retarded adults at Madison, WI, has functioned well - but staffing has been extremely heavy, and in addition, assistance has been provided by graduate students in special education courses from the University of Wisconsin. To compare this with a typical group home in a small community far from a university setting is illogical and should not be the basis for massive change.

Those who originally devised the concepts embodied in S. 2053 have tried many approaches to improving conditions for retarded people over the years. They are to be commended for their efforts. At the same time, it should be recognized that none of their successive approaches (more money for institutions; large community-based residential facilities; smaller group homes, etc.) have totally met those needs, and each has been abandoned in favor of a new idea, the latest of which is S. 2053. To assume that S. 2053 is the perfect answer, without sufficient data and research to support it, is a poor basis for doing away with excellent facilities (such as Bethesda) which are currently meeting needs of thousands of retarded people.

The result of this bill has been to alienate and polarize groups and organizations which have the same goal: improved opportunities for retarded persons. It would seem, therefore, that it is time to agree on certain basics and then work together to find the best solutions. Those basics include the following:

A. Services must be determined by the needs of the individual - not dictated by a preconceived mind-set which says (without adequate proof) that BIG is always BAD, and SMALL is always GOOD. As reported in Sharon Landesman-Dwyer's 1981 study, "Living in the Community," (American Journal of Mental Deficiency, Vol. 86, No. 3), excellence is determined by staff attitude and by enthusiastic and creative leadership.

B. Costs of proposed programs must be assessed fully and appropriately, in fairness to Congress and the taxpayers. This must be achieved by comparing apples with apples. In figuring the costs of a group home, for instance, one cannot merely itemize basic care but must also include the additional services required. When an individual needs therapies, medical help and psychiatric care, it will cost as much or more to provide the same services in the community as it does in an institution, because, in addition to the fees of the professionals involved, one must also include transportation and the staff time to provide the transportation. Moreover, group homes which have been started in recent years to serve those with behavioral problems are already encountering high staff turnover and very high costs. For instance a group home of this type in Minnesota is now charging $120 per day.

C. Solutions must not use the law to violate basic American principles, such as states' rights and the encouragement of private enterprise. We must remember that government exists to do for people that which they cannot do for themselves. Since we cannot do everything for everybody, nor would we want to, we must then concentrate on the areas of greatest needs. In the field of mental retardation, this means providing services first for those who are severely and profoundly retarded - and not jeopardizing the good services which now exist for them. It also means not reducing their already limited freedom of choice, and it means learning from the bad experiences which mentally ill people have suffered because of deinstitutionalization programs.

Therefore, we propose the following:

A. Let's begin by insisting that existing laws be enforced for every institution in this country. Wisconsin has excellent inspection and enforcement; the federal government should make sure that other states do likewise. This alone would assure improved programming and eliminate abuse in all institutions. If we can't enforce those laws now, how can we hope to enforce them in thousands of new group homes and foster care homes in communities across this land?

We second Landesman-Dwyer's recommendation to the President's Committee on Mental Retardation in her 1981 study: "Develop a useful typology of residential facilities and services. Discard terms such as institution, community-based residence, and deinstitutionalization, none of which convey or imply information about program content or quality."

B. Authorize funding for group homes on the same basis as for institutions by expanding the Medicaid waiver and giving that concept permanence. As we supplement rather than replace institutional care, the reduction and elimination of institutions will automatically occur if the various community living options do indeed prove workable and beneficial. People will clamor to participate in obviously good opportunities.

It takes time to develop good programs - more time than S. 2053 allows. In our impatience to cross new bridges, let's not destroy those bridges as we cross them, thereby cutting retarded persons off from that which is excellent in the present.

As M.J. Begab noted in 1975 ("The Mentally Retarded and Society: Trends and Issues," University Park Press, Baltimore), "it must always be kept in mind that the heterogeneity of the retarded population and the diversity of their needs militates against any single pattern or program."

C. Again we quote the Landesman-Dwyer study: "As much as possible, assess the quality of life from the viewpoint of individual clients - their personal preferences, needs and capabilities - rather than from our own perspective (e.g., 'Would I like to live here?')." All too often, in our zeal for doing good, we assume that what is best for people of normal intelligence and emotional stability is automatically best for those who are very retarded, those who have behavior problems and those who are elderly (and in some instances have died when forced to move to another home).

I would not want to live in a neighborhood surrounded by Einsteins - I would feel uncomfortable and out-of-place, never quite as good as anyone else. I most likely would have few friends and would be the object of the neighbor's pity or ostracism. Yet this very situation is what ALL profoundly retarded people could be subjected to if S. 2053 becomes a reality - and they will have no place to return because the good institutions which now exist, the good institutions where they have found friendship and help and safety, the good institutions where they have made progress will no longer be an alternative for they will be closed.

Moreover, it takes time to change community attitudes, to train staff, to set up protections and programs - more time than S. 2053 allows. It took us three years to establish our second Illinois group home. We have been trying for an equal length of time to open a home in Maryland, but state requirements for education of staff make it almost impossible to find applicants. Iowa has laws requiring a group home staff person to be certified for distribution of medication, but fails to offer the certification course. An appropriate St. Louis site has proven difficult to find. GOOD group homes do not happen overnight.

Opportunists, lured by the potential for profit, are already entering the group home field in anticipation of passage of S. 2053. At the 1984 convention of the American Association on Mental Deficiency in Minneapolis, one organization was telling all who stopped at its display, "Do you know of any available group homes? We're buying."

Therefore, let us proceed under the Medicaid waiver to establish and test new programs. Let us move slowly and carefully, not through S. 2053, but through trial and testing until there is sufficient documentation to assure success rather than experimentation with the lives of precious people - our retarded friends and clients.

STATEMENT BY GERALD WALSH, EXECUTIVE DIRECTOR, MOUNT OLIVET ROLLING ACRES RESIDENCE, ON BEHALF OF THE MINNESOTA NETWORK OF NOT-FOR-PROFIT PROVIDERS OF MENTAL RETARDATION SERVICES, MINNEAPOLIS, MN

Mr. WALSH. The Minnesota Network of Not-For-Profit Providers of Mental Retardation Services represents eight medium-sized Minnesota providers who serve 687 persons in facilities ranging in size from 36 to 103. We are members of the Association of Residents for the Retarded in Minnesota, which has a position substantially the same as ours. ARM has 270 member facilities who provide residential facilities for 3,914 persons. We are in opposition to S. 2053 as proposed.

Minnesota, as you know, has been a trailblazer in services for children and adults who are mentally handicapped. We have developed a broad spectrum of interrelated high quality programs. Our State institutions which served 6,200 persons at three sites in 1969 serve only 2,170 persons at seven sites in 1984.

In Minnesota in 1982, 47 percent of those in ICF-MR community residential facilities lived in homes for over 15. The total served in community residential facilities is over 5,000.

In Minnesota, a significant number of mentally handicapped who reside away from their families live in homes, and live in one of the 41 medium-sized facilities for over 15 residents. S. 2053 would, based on the theory that smaller is better for everyone everywhere, regardless of the degree of handicap and special needs, seriously would disrupt Minnesota's residential programming. Such a radical change in residential services would also have a severe effect on day programs and other services which have developed along with and in support of residential services.

A study by the federally funded University of Minnesota Department of Education, Psychology Center—University of Minnesota Educational Psychology Center for Residential and Community Services, which was just released, compares the facility close/move rate for residential services nationwide. This study says that in recent years there has been growing concern among parents and advocates regarding the stability of community-based residential services. Entitled "Stability of Residential Facilities for Mentally Retarded People," it very graphically shows vast differences among States and between States in the stability of residential services for mentally handicapped people over a 5-year period.

In Minnesota, only 7.5 percent of the facilities for 16 to 63 closed or moved over the 5-year study, compared to 29.9 percent nationwide—well over three times higher. This study reports also that 41.4 percent of the facilities for between one and six residents closed between 1977 and 1982—41.4 percent.

In summary, it is clear that Minnesota, like each State, and like each mentally retarded individual, is unique in characteristics and thus in need. To narrow the range of services would be to reduce the options available to the residents of Minnesota. The result we feel would be an overall reduction of the quality of care and services for mentally handicapped persons.

The number "10"—three times the Minnesota average household size of 3.4, is both arbitrary and restrictive. Imagine the necessary size of special homes for 10. These would not fit into most normal neighborhoods.

Also, assigning the term "institution" to facilities for over 10 in existing communities, as this bill has done, is an outright misnomer. There is the mistaken impression that groups of retarded persons up to 10 would be wholeheartedly embraced by the neighborhood, and if over 10 totally rejected. Both assumptions are false, but the second is erroneous and dangerous when used as a major reason to severely restrict facility size.

The need for diversity of services is explained by Senator Robert Dole, chairman of the Senate Finance Committee, as follows. He says: "With respect to the disabled, as with any other single group, obviously no one solution is best for all." I believe that the proposed legislation is too simplistic to be effective. It suggests that we eliminate the present system which was developed through years of experience and change, and adopt another based primarily on theoretical ideas about size.

There is, in my readings, no evidence which shows that S. 2053 would be cost-effective, either. Network administrators, our group who have done their own cost studies, concluded that it would be more expensive to care for an individual in a home for 6 than in one for 24, and in some cases it has been shown to be totally impractical from a financial and humane view to put a resident requiring certain specialized care procedures in a small facility.

All of these factors should be considered regarding S. 2053.

Senator DURENBERGER. Thank you.

Jon Nelson.

[Mr. Walsh's prepared statement follows:]

THE MINNESOTA NETWORK OF NOT-FOR-PROFIT PROVIDERS OF MENTAL RETARDATION SERVICES

The Minnesota Network of Not-For-Profit Providers of Mental Retardation Services (hereafter referred to simply as "the Network") is composed of representatives from eight organizations including: Hammer Residences, Clara Doern Residence, Lutheran Social Services , Hiawatha Homes, Dakota's Children, Inc., Muriel Humphrey Residences, Homeward Bound and Rolling Acres. The organization is a forum to exchange ideas and unify concerns regarding the success of existing care methods, and to explore possibilities that might lead to more comprehensive and cost-effective care in the future. This group represents the care standards afforded to 687 residents. It is because we, as medium-sized facilities which serve between 36 and 103 persons, believe services at our locations (and those like ours nationwide) will be adversely affected by bill S.2053 that we stand united against passage of the bill in its current form.

IDENTIFICATION

Introduction

Minnesota has always been recognized as a leader in developing care for the mentally retarded. As the de-institutionalization revolution swept America in the early 1970s, this state was in the forefront in unfolding comprehensive, sensitive answers to difficult questions. By the 1980s, Minnesota had clearly established itself as a trailblazer in services for the mentally handicapped, having shifted significantly more than 50 percent of its residents from large, institution-like facilities to smaller ones. In 1969, about 6200 residents lived in state institutions. At that time, only about 500 persons (this estimate is likely high) lived in neighborhood facilities. But in 1984, thanks to the success and prevalence of medium-sized facilities in the state, only 1800 remain institutionalized. A significant numer of these mentally handicapped persons are now served by Minnesota's 41 medium-sized facilities (which have more than 15 residents, and unfortunately, would be adversely affected by bill S. 2053.

In effect, they provide the neighborhood influence and residential atmosphere available in a home, which bill S.2053 espouses, but unlike the proposed legislation, these facilities are also equipped to deal with those patients who need constant or specialized attention because of age, or reasons of physical, psychological or emotional health. Furthermore, these sites provide stability of staff personnel. A study by the University of Minnesota used a concept known as the close/move rate to give an indication of stability. This index gives a percentage yearly turnover for facilities handling mentally handicapped persons. Nationwide, the close/move rate was 42.1 in 1983, while

Minnesota -- dense in medium-sized facilities -- was strikingly below the average, at eight percent. The study found that "one method of increasing stability noted in the research was through ICF/MR certification." It is interesting to note that all of Minnesota's group residences are ICF/MR certified.

The point is that the state is already doing a tough job well. To make arbitrary alterations in the way the system will carry out its function, we think, would be a mistake.

In summary, it is clear that Minnesota, like each state, and like each mentally retarded individual, is unique in its characteristics, and thus in its needs. In order to meet these needs, it has devised a broad range of services to meet the broad and complex range of situations among mentally handicapped persons. That is, in striving to become conscious of the uniqueness of each mentally retarded person , Minnesota Network Administrators have accordingly developed a spectrum to meet those needs. To narrow the range of services, as S.2053 would do, would be to reduce the options available to residents of the state, and to inhibit our abilities to meet the needs of certain persons unique to their given age, physical abilities, physical health and level of mental retardation. The result would be an overall reduction of the quality of care and services for the mentally handicapped. Specifically, we wish to make four broach points, and then develop them: Bill S.2053, in its current form, would reduce and eventually eliminate on-going Medicaid assistance to residents at homes with more than 10 persons living there (3 x Av. Minn. Household of 3.4), 2) Most sites that care for more than 15 persons are not "institutions," 3) There is no conclusive evidence that "small is better," 4) thus in conclusion, it is the position of the Network that S.2053 offers an oversimplified answer to the very complex question of how best to care for the mentally handcapped.

Phasing out medium-sized facilities

Proponents and opponents of Bill S.2053 disagree on many things, but one point on which there is no variance is that funds will be withdrawn from mid-sized facilities over periods of ten or 15 years with no compensating factor. In effect, a major source of funding -- and thus a primary assurance of a certain level of services -- will be stripped away. And since there will be nothing to bridge the newly-opened gap, many of these facilities will close.

There are those who would argue that S.2053 would "not actually close down" these facilities, but merely withdraw Medicaid funds. But what other effect would it have if families who now have children with us are given two alternatives: move your kids, or lose Medicaid benefits. Surely most of these families will not be able to entirely bear the financial brunt of keeping their child where he is, and thus a de-stabilizing move will occur that will have immediate negative effects for the resident, and immediate devastating effects on the system. To one who would argue that Bill S.2053 does not deny freedom of-choice, we would counter that yet, you are correct, but only within the context of complete financial security. But as we know, mental retardation knows no sexual, racial, ethnic, national, social or economic bounds.

Network members have noted with some alarm that the facilites being disassociated from Medicaid are at no time urged to maintain quality during the period of transition. The bill never mentions what is to become of those who exersize their right to choose, but become entangled in a mess of shifting governmental priorities as the quality of care at those medium-sized facilities drifts away long before the last resident leaves.

Institution?

Perhaps this position statement should have begun with a discussion of the word "institution." Webster's New World Dictionary defines it as "an organization having a social, educational or religious purpose, as a school, church, hospital, reformatory, etc. By this definition, not only are small and medium-sized facilities "institutions," but *every facility which services more than one resident is, too.* Ridiculous? Well, how many people make an organization? A group? And who determines this? Our point is that the number 10 (three times the averge Minnesota household of 3.4) is both arbitrary and restrictive. Further, assigning the term "institution" to community-based servic facilites which likely will afford retarded persons the same amount of *actual contact* with neighbors as smaller group homes is an outright misnomer.

We believe there has developed somewhere along the way the mistaken impression that if groups of retarded persons get together, they are treated like lepers, and conversely, if there are only a few, they will be wholeheartedly embraced by the society at large. Both are false, but the second assumption is erroneous *and* dangerous. First, in attempting to rescue them from "institutions," some individuals will be thrust prematurely into situations too difficult for them to handle. There are any number of neighborhoods in big cities where people who have lived next door for years do not even speak to one another. How then, do we arrive at this naive, simplistic (though hopeful) answer to the problem, believing that "just letting them be normal" will make everything OK.

The Need For Diversity

The need for diversity was likely best explained by the senators themselves. Bob Dole, chairman of the Senate Finance Committee: "I am anxious to examine all options, including a movement toward community-based services. But with respect to the disabled, as with any other single group, obviously no one solution is best for all. I am anxious to examine all options including a movement toward community-based care in the hope of coming to agreement on the best mix of services."

And Dave Durenberger, chaiman of the finance committee's subcomittee on health: "Senator Chafee's intent to de-institutionalize where appropriate should be applauded, but closing all state institutions would be a grave mistake. We need to develop a continuum of care to meet the varied needs of this population grop and to provide alternatives so that "choice" can be realized."

But this legislation would undermine diversity. S.2053 would phase out federal funding for "large" institutions over a 10-15-year period, depending on when the facilities were developed (15 years for facilities housing 16-65 residents, which opened within five years of the date the bill would be enacted, and 10 years for all other facilities with 16 or more residents.

Conclusions

Our conclusions are simple. The proposed legislation is too simplistic to be effective. It suggests that we throw out a tried and proven system of care for the mentally handicapped, and adopt another based on nothing more than theoretical ideas about size. There is no conclusive data which states it would be cost-effective either. In fact, Network administrators who have done comparative cost analysis studies have found it more expensive to care for an individual in a 6-bed, than a 24-bed facility, and in some cases, it is been shown to be totally impractical from a financial standpoint to put a resident requiring certain specialized care procedures into a small facility. The senators should consider all these factors. We have. ..

STATEMENT OF JON NELSON, EXECUTIVE DIRECTOR, CHRISTIAN COMMUNITY LIVING SYSTEMS, INC., WATERTOWN, WI

Mr. NELSON. Chairman Durenberger, Senator Chafee, thank you for this opportunity today to speak to Senate bill 2053.

My name is Jon Nelson. I am executive director for a private provider of services in southern Wisconsin, headquartered in Watertown, WI. I speak today not only representing ourselves as a private provider but also as the brother to an individual who has Downs Syndrome, as well as a number of professional organizations of providers in the State of Wisconsin, namely the Community Living Alliance for the Mentally Retarded, the Wisconsin Chapter of the Association for the Severely Handicapped, the Developmental Disabilities Division of the Wisconsin Association of Community Human Service Programs, the United Cerebral Palsy of Wisconsin, and a number of specific individuals who at one time or another had lived in institutions and are now living in community-based programs or completely independently on their own.

We are firmly convinced that community-based programs can not only serve the needs of all individuals but that they can do it with more dignity, with more success, and much more efficiently.

Community-based services offer, among other benefits, more personal interaction and attention, as well as more programmatic attention. An example of this is evident in a number of studies but particularly the Penhurst Longitudinal study, which indicates that individuals now living in community services are receiving approximately 10 hours of program per day, versus the 6 hours which they received while at Penhurst.

Community-based services have also demonstrated their competencies in providing services to individuals with all types and degrees of disabilities and medical needs. Again, to illustrate, the State of Wisconsin has since December 1983 under its title XIX waiver program entitled 'The Community Integration Program' moved 22 individuals into community services. Eight more are scheduled to move during August, and they anticipate that they will be moving approximately 100 individuals per year over the next several years. Most of these individuals are severely involved either with a particular disability and/or with behavioral problems or medical needs. The individuals who have moved since December are doing extremely well in community-based settings. In fact, staff from one of the institutions has almost denied that they are the same people who left the institution in December.

Another pilot program in Wisconsin, the Family Support Program, has during the past 6 months demonstrated that with very little additional cost of an average of $107 per month per family, that families can be helped to keep their sons and daughters at home instead of being placed in an institution. Again, one such case involves a family whose son, if he were not being served by that family, would have been placed in an intensive care unit in a hospital. As a result of severe complications with pneumonia, he is now confined to a wheelchair, needs to be on a respirator 24 hours a day and fed through a tube. He is at home; he is out in the community; he appeared in Madison to testify at a hearing earlier this year.

Other well known examples can be found in the Encore Program located in Omaha, NE, as well as the Macom-Oakland region from Michigan which we heard about today.

Community-based programs also allow for greater programmatic flexibility. They are able to meet the needs of individuals rather than to force the individuals to fit into the parameters of an established program. This also allows for greater movement out of the program into less restrictive settings.

Nor are community-based programs dependent for their survival on keeping individuals in the system. They can very easily be changed to serve other needs and can be phased out completely if no longer needed—an option which obviously causes institutions some problems in light of 2053. This characteristic also allows small community-based programs to be monitored and regulated with greater efficiency and ease, as they are much more visible to the general public as well as to the contracting and regulating authorities. If compliance is not gained, a small community-based program of 6 or 8 individuals can be much more easily phased out and the people relocated than is possible in an institution of 100 or 200 or 500 individuals.

Community-based services have also demonstrated their effectiveness in controlling costs. While for some few individuals the initial cost might be more in the community-based program, studies have also shown that in by far the majority of cases those initial costs very rapidly decrease after the services have been provided, as a person demonstrates their growth and development in that program.

Over an individual's lifetime, the savings of literally tens of thousands of dollars, and in some cases hundreds of thousands of dollars, can be realized in providing services in small community-based programs.

We have heard about staff costs and other administrative costs which are typically higher in institutions than in community-based settings.

One comment as far as the freedom of choice. I would offer that, today, because of the lack of the number of community-based programs which are needed, that in effect individuals have no choice today. For every parent or individual who would like to remain in an institution, I could probably come up with half a dozen, 8 or 10 parents and/or individuals who would like to be placed in community settings but cannot because they do not exist.

Community services are indeed lacking in some areas. There needs to be extensive expansion of such services, but there is a lack of funds to do so. There needs to be much more intensive staff training, but there is currently is a lack of funds to do so. There needs to be an upgrading of wages and benefits paid to staff and community-based programs, but again there currently is a lack of funds to allow this. There needs to be much more public education and an improvement in generic community resources and support services—but, again, the funds are lacking.

In summary, there simply is a lack of appropriate funds for community-based programs. This is due to the fact that by far the majority of all of our dollars for human services are now being pumped into institutional programs. Senate bill 2053 proposes to change all of that. Not only can this legislation direct funding to be more effective and meaningful, but it is the opportunity to change the very philosophy behind the provision of services to individuals who have disabilities and intensive medical needs.

Senate bill 2053 can take the lead in showing that we value people, we respect their abilities as well as their disabilities, and we are committed to use our resources, both financial and human, to achieve the highest good in the most efficient and productive manner.

Thank you.

Senator DURENBERGER. Thank you very much.

Lyn Rucker.

STATEMENT OF LYN RUCKER, EXECUTIVE DIRECTOR, REGION V MENTAL RETARDATION SERVICES, LINCOLN, NE

Ms. RUCKER. Chairman Durenberger, Senator Chafee, my name is Lyn Rucker. I am the executive director of Region V, Mental Retardation Services, in Lincoln, NE.

It is with a great deal of pleasure that I come here today to stand in firm support of the Community and Family Living Amendments of 1983.

Region V provides community-based day and residential services to over 550 persons with mental retardation in 16 counties of southeast Nebraska. Of those individuals, 139 have severe or profound mental retardation, and 102 are classified as being "high need" due to physical, medical and/or behavioral characteristics. We serve 290 persons residentially, nearly all of whom live in a home with five or fewer persons. There are only two exceptions in region V: one house has six, one house has seven; they are scheduled to be phased out.

All of the individuals we serve in day programs are involved outside of their homes in locations such as work stations in industry, supported employment, competitive employment, or region V industrial sites. We are involved in integrating individuals with all levels of need into towns with populations from 200 to 200,000 as 15 of our 16 counties are rural.

Our years of providing community programs and services offer eloquent support to medicaid restructuring. This experience has taught us many things, at least four of which are relevant here.

First, persons with all levels of retardation thrive in the community;

Second, services are efficiently monitored;

Third, service costs are significantly less in the community; and

Fourth, systems can be and are organized both in rural and urban areas.

Out of deference to time, I am not going to go into every one of those areas, but let me start with what I perceive as the most important, and that is that persons with all levels of retardation thrive in the community.

A recent study published in the spring 1984 Journal for the Associations for Persons with Severe Handicaps, also known as the TASH Journal, compare data on certain persons served in our program with counterparts served in an institutional setting. The study results give compelling support to S. 2053—first, that the IQ's or the functioning level of persons living in the community is generally going up, while the functioning level or IQ of persons in the institutions is going down. In addition, the study absolutely confirms what experience has taught us—namely, that the more handicapped the individual, the smaller the living environment must be. Let me say that again: The more handicapped the individual, the smaller the living environment must be.

I have had opportunities to work with the Federal court system and with the State of New York as well as other States. There are providers not only in Nebraska but in Colorado, in New York, Michigan, providing services in six-bed or less facilities for the most medically fragile.

Services in fact do cost less in the communities than in institutions. A study conducted by Touche-Ross & Co. comparing the two models in Nebraska—the findings concluded and analysis has demonstrated that not only are current costs per client less in the community but "the ccst may be reduced further in the community as clients achieve community-living skills" and I quote from the study.

As institutional behaviors are eliminated and community residential living skills are learned, the cost of serving the institutionally placed client should be reduced. I have a copy of that study which I would like to leave here for you today.

The cost in region V for a full-service client—that is, an individual receiving day residential and support services—is $20,000 a year. The cost per comparable person in the institution in Nebraska is $38,000 a year. If you take the mentally retarded, mentally ill person in the psychiatric unit of our regional center in Lincoln, the cost exceeds $50,000 per year.

The systems can be and are organized in both rural and urban areas of the country. For purposes of this hearing, suffice it to say that the provision of services to persons with severe/profound/behavioral/medical needs in rural communities is not uniquely difficult, but it depends to a great extent on one of the traditional strengths of the community system—specifically, sharing resources. The foundation principles of placing the decisionmaking as close to the individual as possible, regularly involving consumers and consumer representatives, seeking and responding to community vigilance and maintaining contacts with the medical and professional support personnel are just a few of the fundamental components of a quality community program, regardless of the functioning level of the person served.

This is 1984. Technology to serve all persons in the community regardless of their handicapping condition exists today. The major limitation to serving everyone on the community is the money with which to do it. S. 2053 would substantially eliminate that barrier and substantially eliminate the violent response to a disability that institutionalization represents.

[Ms. Rucker's prepared testimony follows:]

Chairman Durenburger and Senator Chaffee, it is with a great deal of pleasure that I come here today to testify in firm support of S. 2053.

My name is Lyn Rucker, I am the Executive Director of Region V Mental Retardation Services in Lincoln, Nebraska. Region V provides community based day, residential and support services to over 550 persons with mental retardation in the sixteen counties of Southeast Nebraska. Of those individuals, 139 have severe or profound mental retardation and 102 are classified as being "high need" due to physical, medical and/or behavioral characteristics. We serve 297 persons residentially, and nearly all live in a home of five or fewer people. There are only two exceptions in Region V; one house has six persons and one seven. All of the individuals we serve in day programs are involved outside of their homes in locations such as work stations in industry, supported employment, competitive employment or Region V industrial sites.

Region V has been actively involved in deinstitutionalization for over fourteen years. We believe that all persons, regardless of the severity of their handicapping condition, will ultimately live in complex, heterogeneous integrated community settings. Therefore, our policies prohibit any entrance criteria, other than the diagnosis of mental retardation. We are involved in integrating individuals with all levels of need into towns with populations of from 200 to 200,000. Fifteen of our sixteen counties are rural.

In 1969 there were 2200 persons with mental retardation confined to the one mental retardation institution in Nebraska. Today there are still 460.

Through the 60's and early 70's opponents to deinstitutionalization maintained that persons with severe/profound mental retardation could not be moved to the community -- but they have been moved to communities in Nebraska.

Then it was said that persons with behavioral disorders associated with mental retardation could not successfully be served in the community -- but they were and are in Nebraska.

Then it was maintained that mentally retarded persons with serious medical needs required institutional care forever -- but persons with such needs are now living successfully in the rural and urban communities of Nebraska.

Since the community placement of all persons, regardless of the level of handicapping condition has happened, is happening, and should continue to happen, the financial security implicit in S. 2053 must be accorded to retarded citizens living in community facilities throughout this Nation.

The great advances realized in integrating citizens with mental retardation into rural and urban areas of this country during the past twenty years must not be forfeited. Inadequate funding for community programs threatens just such a setback. Yet, outmoded, segregated, institutional models of care continue to enjoy almost unlimited federal funding. The Community and Family Living Amendments thus are designed quite properly to change that anachronism. I stand in full support of that change.

Fifteen years of providing community services to persons with mental retardation in Nebraska provides eloquent support for Medicaide restructuring. The Nebraska experience has taught us that:

Persons With All Levels Of Retardation Thrive In The Community

Services Are Effectively Monitored

Service Costs Are Significantly Less In The Community

Systems Can Be Organized In Both Rural And Urban Areas

J. Persons With All Levels Of Retardation Thrive In The Community

I want to reiterate that community programs no longer need to justify their existence nor defend their worth. Quite the opposite is true. Since we know that people with complex disabilities can be well served in community settings, we must ask why the violent solution of institutionalization is ever justified.

I raise this issue because some opponents of S. 2053 cite studies which indicate that persons with severe disabilities "do better" or "are happier" in isolated, segregated settings. Those of us who work in community programs may be faulted for letting this type of research go unchallenged. The difficulty is that most community programs are not research oriented. Our time and our money is aimed at directly serving people with mental retardation. Further, many community programs are similar to Region V in terms of research policies. We set high standards for any research conducted in our programs. The privacy and dignity of persons with mental retardation must be respected. We will not condone research practices which violate that privacy and dignity.

Therefore, it was with great satisfaction that we reviewed the results of a recent study which honored our research requirements. The study, published in the Spring, 1984 Journal of the Association for Persons with Severe Handicaps, compared data on certain persons served in our program with counterparts served in an institutional setting. Titled "Changes in Labels of Mental Retardation: A Comparison of Institutional and Community Programs", the study stated,

> ". . . the common wisdom that persons with severe and profound mental retardation should be served in large congregate settings is called into question. In fact, it might be argued that greater needs dictate smaller settings in which effective training, environmental stimulation, and life-style management can be ensured."

I would like to submit this study as part of the record today.

The above cited study absolutely confirms what experience has taught us, namely, that the more handicapped the individual, the smaller the living

living environment must be. We stand firm in our position that people with all levels and types of disabilities should be served in community settings. If we commit ourselves to this approach, we can avoid wasting time and resources in trying to prove or disprove the efficacy of what is, I repeat, a violent response to the presence of a disability: institutionalization.

Because S. 2053 is ultimately about individual lives, I want to close this section with a vignette about a real person. I will call him David, although that is not his real name.

David entered a community program in Region V in 1982, after thirty-eight years of institutionalization. He was labeled as having severe mental retardation and like so many persons who leave the institution, he took medication for a "behavior disorder". He was considered a "major behavior problem." Staff in our agency were cautioned by the institutional staff to expect aggressive and frequent behavioral outbursts.

Today, less than two years later, David no longer takes medication for a behavior disorder. He is highly regarded by all persons with whom he works. His initiative and follow-through are superb. He likes to work. He occasionally displays temper, but he is not regarded as a person with a behavior problem, by any means.

The director of the program in which David is served, David Merrill, Region V-Fairbury, was asked to identify the variable(s) which he believed made a difference in David's life. Merrill said, "I remember the first week he was here. I dropped by his house after work one day and David was relaxing with a cup of coffee. It was apparent that he loved having the opportunity to make choices. It was like, 'I'm coming home to my own house. I can unwind in my own way' It seems so ordinary. But it appears to be the key. Just the environment. Just the expectation that he could make choices."

I ask you to look beyond labels when you consider S. 2053. Look at David, and the thousands like him, who do not deserve institutionalization simply because it appeared to be a good idea a hundred years ago. I urge you to give S. 2053 your full support.

II. Services Are Effectively Monitored

The key word here is "effectively". Community programs, we have learned, possess the capacity to combine traditional and non-traditional monitoring systems in a way that multiplies safeguards to the system and for persons with mental retardation.

Traditional service monitoring includes such procedures as accreditation and licensure. Region V is accredited by the Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled People (AC MRDD). A Region V agency was, in fact, the first community program to be so accredited. While AC MRDD accreditation is voluntary on our part, we believe that programs serving persons with mental retardation should be monitored by external agencies. We are pleased that this concept of external review is a part of S. 2053.

Licensure is another traditional procedure which safeguards service quality. In Region V, all residential facilities operated by the Region, of which there are 45, are licensed.

The point is not that Region V has uniquely achieved accreditation and licensure. Rather, the point is that the traditional controls of accreditation and licensure are in place and are available to monitor community programs everywhere. In other words, the same mechanisms which the better universities and hospitals have always relied upon to assure service quality are equally available in the community.

But community programs have something else. The non-traditional, or more precisely, the <u>natural</u> system of community vigilance is available only in the community. The isolated, insular institution, with its physical, psychological, and spiritual separation from everyday community life cannot avail itself of families, friends, neighbors, and professionals who interact every day with persons who receive our services. In Region V, we receive this feedback daily from people who owe us nothing, and we have come to expect constructive criticism concerning the effectiveness and humaneness of our services.

Even the most mundane areas of the service are critiqued by this method. For example, a parent drops by a group home unannounced near supper time. This parent wonders about the menu. It seems somewhat high in calories. The next day we get a telephone call. "How are menus planned?", we are asked. "Who reviews them? How are special diets prepared? Are individual likes and dislikes taken into account?" We explain that menus are prepared in advance and reviewed by a nutritionist, that our staff assist with all kinds of special diets, and that individual preferences for food are taken into account. We also follow up on the parent's concern. If there is ever a problem, we need to know about it.

Or consider a recent incident in one of our small town programs. A neighbor of a typical four-person group home contacted the agency. She had become acquainted with the women living next door to her. She was also somewhat acquainted with the staff. She became troubled by one such staff person. She said that she had not observed the same type of family-like interaction between this staff person and the women living there as she had observed between other staff and the women. Specifically, she observed a staff person raising her voice to one of the women. While this may sound trivial, the point is that this was quickly exposed and dealt with before it could develop into anything more serious. It has been my experience that such inappropriate staff behavior is not caught in institutions until it develops into a major incident, in some cases threatening the health and safety of the persons served.

It should be apparent that I am not presenting Region V or any community system as immune to the carelessness and even the abuse which has characterized the institutional treatment of persons with mental retardation far too much. What I am saying, with total conviction, is that the best monitoring system we know of, the best safeguard anywhere, is public scrutiny. Again, I emphasize that this is uniquely available to community programs. That is, institutions, by their very nature are isolated from such scrutiny.

I have noted that traditional and natural monitoring systems are available to community programs. I want to highlight an additional procedure we use in Region V. This is our own internal quality audit, which we call Systems Review. Each year we involve staff, volunteers, and outside experts in a thorough review of Region V's services. Systems Review is designed to be the most demanding of all formal review procedures. We believe that if we are self-critical and that if we consistently strive to improve services, we will be in a much stronger position to welcome all other evaluations.

Another very critical external monitoring system built into the Region V system is the Program Ethics Committee. This regional committee meets monthly to review restrictive procedures approved by the local agencies' Behavior Management Corps Teams. Membership on this committee is diverse. The current committee has an attorney, a psychiatrist, two psychologists, two parents, a clergyman, a representative from People First of Nebraska, a program specialist from another agency, and a public policy specialist. This committee provides independent oversight on all questions involving restrictions and psychotropic medications.

This brief sketch of monitoring systems available to community programs is by no means comprehensive. I have not discussed, for example, Region V's Client Advisory Committee made up of consumer representatives from each Region V agency.

I have not explained how the human scale of community programs works as a safeguard for persons who receive services.

In the final analysis, our particular monitoring system is not the issue. Our system is simply an example of the depth and breadth of monitoring systems available in community settings. It is a solid piece of evidence that our best instincts (our instincts which tell us to accept persons with disabilities and to bring them into our lives) can translate into workable and accountable service delivery systems.

III. Service Costs Are Significantly Less In The Community

Costs of providing services (even for the most severely handicapped) are less in community programs than institutions in Nebraska. In a study conducted by Touche Ross & Co., comparing the two models in Nebraska, the findings included an analysis which demonstrated that not only are current costs per client less in the community, but the costs may be reduced even further in the community as clients achieve community living skills. "As institutional behaviors are eliminated and community/residential living skills are learned, the cost of serving the (institutional) placed client should be reduced."[1]

The average annual cost for an individual receiving a full range of day and residential services (including transportation, Social Services, and Administration) in Region V is $20,193. The average cost in the mental retardation institution is $38,008 and the costs in the MR/MH units of the Regional Center (psychiatric hospital with limited facilities for mentally retarded persons with psychiatric problems) exceeds $50,000 per individual. Even if we were to single out one of the Region's most expensive programs (the agency at Fairbury for high

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[1] Cost Study of the Community Based Mental Retardation Regions and the Beatrice State Developmental Center, p. 54, (August 15, 1980).

need persons), the cost per client, $26,332, is still significantly lower than institutional costs.

There are several reasons for the tremendous cost of service differences between institutions and communities:

- Institutions have a high proportion of relatively inflexible overhead costs (for example, building maintenance, grounds, utilities, medical services, and administration). As institutional populations go down, the costs per person go up because of the inelastic nature of such institutional costs. In my experience, this factor alone provides a strong motivation for institutional staff and state officials to unjustifiably keep beds full and capacity up.
- Community programs utilize small homes with the "family" (clients and staff) participating in routine cooking, cleaning and home care. As an active participant in that family unit, clients develop residential living skills. Institutions, on the other hand, employ or contract for food service and custodial workers in addition to direct care staff. Skills are not gained by the consumer and costs go up. Moreover, because of the large numbers involved, even if clients were expected to perform such services in the institution, the experience would be one more akin to that of a basic trainee as he spends his first weeks in military service than to normal family living skills.
- Community programs integrate high need clients into homes serving predominately moderate need clients without increasing staff. This approach provides for appropriate peer modeling (i.e., clients watch other higher functioning persons and emulate their behavior), blending within the community, and a lower cost.
- Community programs have the flexibility to recognize the client's

independent living skills. As a result, the community has the opportunity to serve a blend of low, moderate and high need individuals in less costly programs. This is not true in most institutions. In institutions, because of the large numbers involved, you get the same full range of care whether you are low or high need. Individuality of service, training and costs is lost in the institutional model.

IV. Systems Can Be Organized In Both Rural And Urban Areas

The state of Nebraska is divided into six geographical regions for purposes of providing services to mentally retarded citizens. Each of the six mental retardation regions serves persons with severe/profound mental, behavioral and medical needs. Four of the regions consist entirely of rural areas, one (Omaha) consists primarily of urban areas, and one (Region V) has both rural and urban (Lincoln) areas. For persons interested in greater detail on the development of rural programs for persons with high needs, I have provided a paper I prepared for presentation to the Association for Retarded Citizens-Executives Training at National Convention, regarding that topic.

For the purposes of this hearing, suffice it to say that the provision of services to persons with severe/profound mental, behavioral or medical needs in rural communities is not uniquely difficult, but depends to a great extent on one of the traditional strengths of community services -- sharing resources.

The foundation principles of placing decision making as close to the individual as possible, regularly involving consumers and consumer representatives, seeking and responding to community vigilance, and maintaining contacts with medical and professional support personnel are just a few of the fundamental components of a quality community program, regardless of the functioning level of the persons served.

Likewise, when hiring staff, characteristics that are valuable in staff working with any group of persons with mental retardation are sought: experience, attitude/philosophy and creativity.

Judgments regarding S.2053, its passage and amendments should be based on the premise that persons with all levels of mental, physical, behavioral and medical needs are being successfully served in the community. The only limitations to serving everyone in a community setting is the money with which to do it. S. 2053 would substantially eliminate that barrier.

V. Summary

This is 1984. The technology to serve all persons in the community regardless of their handicapping condition exists today. S. 2053 offers clients, parents and professionals the opportunity to unite and focus our energies on the further development of quality integrated community systems designed to serve all persons with disabilities.

I urge you to continue to lead this march to the future. I urge you to focus your numerous resources on making this bill as strong and as supportive of people developing independence as you can. Using your leadership as a model, perhaps the "mental retardation community" can remember that we are here for the same thing: the growth and development of individuals.

I wish to give grateful recognition to Mary Jane Humphrey, Director of Planning and Policy Analysis, Region V, for her assistance in the preparation of this submission.

Changes in Levels of Mental Retardation: A Comparison of Institutional and Community Populations[1, 2]

Kenneth D. Keith and L. Rene Ferdinand

Author Information
Kenneth D. Keith, Ph.D., Psychologist, Lincoln Center for Families and Children, Lincoln, Nebraska.
L. Rene Ferdinand, Systems Review Coordinator, Region V Mental Retardation Services, Lincoln, Nebraska.

Article Descriptors
changes in levels of retardation; community placement; deinstitutionalization; effects of community placement; effects of institutionalization

Increasingly, persons with complex disabilities are served in community settings, and institutionalization is less often a treatment of choice. However, relatively little work has been reported comparing the community and institution in terms of individual data. This study was conducted in order to compare changes in level of mental retardation among persons served in a community-based service system and institutionalized persons from the same geographic region. Comparisons were made at all levels of mental retardation and of cohort groups matched on age, sex, ambulation, and initial level of retardation. In general, persons in the community were more likely to increase their functioning level, while those at the institution were found to decrease at a higher rate. Particularly noteworthy differences were found within the severely retarded group. The impact of community interaction and stimulation is discussed, and implications for service providers are suggested.

In recent years, the right of mentally retarded citizens to particiapte in society has been increasingly recognized, and institutionalization has become a less frequent occurrence in the United States (President's Committee on Mental Retardation, 1976). Community participation has been enhanced by a variety of educational, residential, vocational, and family services as well as by specialized supports and resources (PCMR, 1979). Although the conventional wisdom has held that certain persons—especially those presenting difficult training, medical, or management challenges—should be served in congregate facilities, it has been shown that community-based programs may serve a population equally complex as that found in institutions (Menolascino, McGee, & Casey, 1982).

In 1974, the President's Committee on Mental Retardation expressed a belief in the ability of persons with mental retardation to continue to grow and develop, if they were provided environments offering the rights and opportunities afforded other citizens. This is a perspective that is often asserted and generally supported by philosophic and legal arguments. Data evaluating the community experience are less often reported, and comparative data on individual persons experiencing community and/or institutional lives are even less common. Nevertheless, a few studies suggest areas of interest for potential investigation Aames and Moen (1976), for example, reported adaptive behavior changes in residents of community group homes; Silverstein (1969) investigated the longitudinal decline in IQ of persons residing in a large institution; Phillips and Balthazar (1979) documented declines in communication during prolonged institutionalization; and Schalock, Gadwood, and Perry (in press) analyzed differential effects of community residential settings.

The present study was conducted in order to compare changes in level of mental retardation, according to standards of the American Association of Mental Deficiency (AAMD) (Grossman, 1973) between persons served in a state institution and those served in a community-based service system.

Method

Programs Studied

The community-based mental retardation (CBMR) services are provided by a 16-county regional agency with seven area programs serving a total client population of 540. These individuals live in a variety of small residential settings, the largest serving seven persons, dispersed throughout the communities. Individuals under age 21 receive vocational services provided by each area program, and generic community services are used for meeting most medical, psychological, and recreational needs.

The institution is a state-operated facility serving 480 individuals with mental retardation. Approximately 30% of the institution's population is from the same 16 counties served by the CBMR. Residential services are provided in cottages serving 16 people or in large dormitory-type buildings. The institution provides for its residents a variety of educational and vocational training programs. Almost all medical, psychological, and recreational services are available at the institution.

Both the institution and community-based program are serving individuals of all ages, abilities, and needs. Both are accredited by national organizations and are monitored by the same state regulatory agencies.

Subject Selection

Existing records from their respective programs (community or institutional) were reviewed for all individuals from the 16-county region. Only those with standardized measures of intelligence and/or adaptive behavior ratings that could be classified by functioning levels based on AAMD standards were considered eligible for inclusion in the study. Assessments and classifications at the institution were typically completed by members of the facility's psychology staff; those in the community were generally done by licensed private practitioners or community mental health center psychologists.

Of those persons meeting the assessment criteria, those who had an AAMD classification on record during or after 1976 *and* who had a subsequent classification assigned after at least three years in the same program, were chosen for the study sample. This procedure produced a sample of 344 individuals with two classifications at least three years apart. The earlier classification was considered the *initial* classification, and the most recent was termed *current*. Of the sample, 198 persons were in the CBMR and 146 in the institution. Analysis of the initial classifications of those in the CBMR showed the following: 58 individuals classified as mildly retarded; 75 as moderately retarded; 31 severely retarded; and 8 profoundly retarded. The remaining 26 persons were nonretarded or in midrange (e.g., moderate-to-mild). Analysis of classifications for those from the institution showed 2 individuals classified as mildly retarded; 11 moderately retarded; 51 severely retarded; and 79 as profoundly retarded; with 3 individuals being nonretarded or in a midrange. Initial classifications for subjects were compared to their current classifications in four different ways.

Comparison 1

Procedure. The first comparison was made between all subjects, institutionalized and community-based, who met the selection criteria described above. Of the 198 persons in the community and 146 residing at the institution, the number whose functioning level had increased, decreased, or remained the same (according to AAMD criteria) was computed. These figures were compared and analyzed in order to ascertain any differences in changes in levels for the entire sample in the two types of programs.

Results. Changes in AAMD classification for all subjects are summarized in Table 1. The tendency for individuals in the community to increase in functioning level was greater than that of persons in the institution, where a greater relative frequency of decreased functioning levels was observed. These differences were found to be statistically significant when subjected to the Chi-Square test of significance ($\chi^2 = 31.39$; $df = 2$; $p < .001$). (Note: in only two cases were changes in classification found to be greater than one level.)

Comparison 2

Procedure. Of the 344 individuals in Comparison 1, 109 were classified as profoundly retarded (87) or nonretarded (22). These subgroups could vary in only one direction with respect to functioning level (the profound group upward, the nonretarded group downward). In recognition of this fact, Comparison 2 was conducted to compare changes in functioning level between the community and institution groups with the profound and nonretarded subgroups omitted from analysis. This resulted in an analysis of changes in level of mental retardation of 65 persons at the institution and 170 persons in the community.

Results. Changes in functioning level for these groups appear in Table 1. As in Comparison 1, the percentage of individuals increasing in functioning level was greater in the community, with the number decreasing being higher at the institution. These differences were found to be statistically significant ($\chi^2 = 62.5$; $df = 2$; $p < .001$).

Comparison 3

Procedure. Two subgroups (the moderately and severely retarded) contained a sufficiently large number of persons to allow statistical analysis of changes in functioning level by subgroups. Of the 86 persons with moderate retardation in the study, 75 resided in the community, and 11 were at the institution. Within the severe subgroup, 31 were in the community and 51 at the institution. Changes from the initial classificatory

Table 1
Changes in AAMD Classification

	N	Mean Age	Increased	Decreased	No Change
Comparison 1—All Subjects					
Institution	146	34.7	11(7.5%)	36(24.7%)	99(67.8%)
Community	198	40.4	59(29.8%)	21(10.6%)	118(59.6%)
Comparison 2—Excluding Profound & Non-retarded					
Institution	65	36.6	8(12.3%)	35(53.8%)	22(33.8%)
Community	170	33.1	58(34.1%)	13(7.6%)	99(58.2%)
Comparison 3					
Moderately Retarded					
Institution	11	34.7	3(27.3%)	2(18.2%)	6(54.5%)
Community	75	31.4	23(30.7%)	4(5.3%)	48(64.0%)
Severely Retarded					
Institution	51	36.2	4(7.8%)	32(62.8%)	15(29.4%)
Community	31	28.9	22(71.0%)	1(3.2%)	8(25.8%)
Comparison 4—Cohort Study					
Institution	21	27.6	3(14.3%)	6(28.6%)	12(57.1%)
Community	21	27.2	10(47.6%)	0(0.0%)	11(52.4%)

levels were compared for both groups, and differences between institution and community were analyzed.

Results. Analysis of changes in functioning levels for the moderately retarded subgroup (Table I) showed no significant difference between institution and community. The percentage of persons with increasing levels of functioning, however, was greater in the community. There was a correspondingly greater percentage decreasing in functioning level at the institution ($\chi^2 = 2.43$; *df* = 2; N.S.)

When functioning level changes between institution and community were studied for the severely retarded subgroup, significant differences were found. Persons in the community were much more likely to increase their functioning level, while those at the institution were found to decrease at a much higher rate ($\chi^2 = 41.38$; *df* = 2; $p < .001$).

Finally, although the mildly retarded and profoundly retarded subgroups were not subjected to statistical analysis (due to sample size), it was noted that the differences were consistent with those observed for the other groups. Within the profound subgroup, the percentages increasing in functioning level were 3.8% at the institution and 25% in the community, with the remainder showing no change. In the mild subgroup, 50% decreased at the institution and 50% remained the same, while 12.1% decreased, and 75.9% remained the same in the community.

Comparison 4

Procedure. Although both the community and institutional programs served persons with all levels of disability and a wide range of ages, it was considered important to conduct a cohort study that would match individuals served in the community with those served in the institution. Accordingly, a sample of 42 persons was selected, constituting 21 matched pairs. These individuals were matched on the basis of age, sex, ambulation, and initial level of mental retardation (14 in each the moderate, severe, and profound levels). A blind matching process was employed to ensure that outcome measures were not available to raters. The pairs ranged in age from 10 to 48 years, with 8 pairs being female and 13 male. Four pairs were nonambulatory. Following the matching process, changes in level of mental retardation for the community and institutional groups were compared and analyzed.

Results. A summary of changes in functioning level for the cohort study appears in Table I. It can be seen that the tendency toward increased functioning levels in the community is repeated here; the observed differences were found to be statistically significant ($\chi^2 = 9.81$; *df* = 2; $p < .01$).

Discussion

In the programs studied here, the trend toward increased functioning levels in the community is clear.

Although the concept of functioning level *per se* is not a precise measure of individual skills and behavior, it is widely accepted as one significant indicator of general developmental status.

The institution studied here has strong capabilities in staff development and programming, maintaining a sophisticated system of daily training and data collection. Therefore, it does not seem likely that deficits in this area can account for the differences found in this study. Thus, even though the institution might become the enriched environment argued for in *Wyatt v. Ireland* (1978), the effects of institutionalization may nevertheless be detrimental.

Vitello, Atthowe, and Cadwell (1983) found that placement from institutions is dependent upon higher levels of cognitive and adaptive functioning. If, as Throne (1977) asserted, intelligence can be increased through training, it might seem reasonable to expect an effective institutional training program to prepare persons for community placement. The data reported here suggest a basic fallacy in this line of reasoning, indicating, instead, the likelihood of a decline in functioning level over time in the institution. This observation is consistent with findings of significant skill losses among institutional residents (Keith & Lange, 1974). On the other hand, when competent programming is combined with community experience, Throne's (1977) expectations seem to be borne out.

The findings of this study, when considered in the context of the broader movement toward delivery of services in homes and homelike settings, suggest several implications for service providers. First, the common wisdom that persons with severe and profound mental retardation should be served in large congregate settings is called into question. In fact, it might be argued that greater needs should dictate *smaller* settings in which effective training, environmental stimulation, and life-style management can be ensured. Second, it would seem reasonable to conclude that environments that are more nearly normalizing can also be effective, if the proper programming components are present. Although it is possible for normalizing environments to preclude effective training (Throne, 1975; Keith, 1979), those studied in the present investigation combined community access and successful programming. A centralized, congregate facility is not necessary to attain this end. Third, the goal of keeping virtually *all* members of future generations in their home communities is not only possible, but is also likely to be effective in enhancing their intellectual and social capabilities, if local programs are properly arrayed.

Over the past two decades, many arguments have been advanced on behalf of community alternatives to institutional programs. Generally, the burden of proof seems to have been on the community to prove its role in the lives of individuals. It becomes increasingly clear that home and community are capable of assuming natural, effective roles for persons with mental retardation, and that the well-worn reasons for disrupting these roles are no longer compelling.

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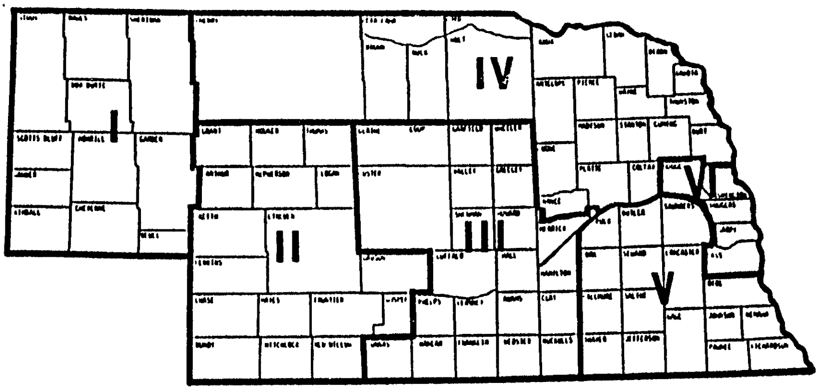
Footnotes

[1] The authors gratefully acknowledge the assistance of the social service workers of Region V Mental Retardation Services, and the technical assistance and support of Robert L. Schalock and Lyn Rucker.

[2] Supported in part by a grant from the Nebraska Department of Health, Division of Developmental Disabilities.

NEBRASKA COMMUNITY MR REGIONS



SERVICES TO PERSONS WITH SEVERE/PROFOUND MENTAL RETARDATION

by

LYN RUCKER

LIFE IS JUST WHAT YOU MAKE IT

or

A Difference You Can See: One Example of Services to Persons with Severe or Profound Mental Retardation in the Community

PURPOSE

The purpose of this paper is to describe how one rural Nebraska community based program for persons with severe/profound mental retardation was established, why it was designed the way it was and what we have learned from that experience. The following topics will be reviewed:

- General background information will be given to familiarize the reader with the structure of services offered in Nebraska, specifically Region V.
- A description of one program which was specifically designed to provide services to persons with severe or profound mental retardation, behavior or medical needs will be provided.
- What we have learned that works and does not work will be discussed.
- The Costs for this program will be summarized.
- Conclusions and recommendations will be shared.

BEFORE WE BEGIN

There are a variety of reasons why a system works or doesn't work for all of the people for whom it has been conceived. Given the limited scope of this paper, it is impossible for all of the components that are critical to a successful program designed to serve all persons regardless of the severity of their handicapping condition to be discussed. However, as those critical positive components or attitudes present themselves in this paper, they will be underlined for emphasis.

If I were to identify the primary reason why every region within Nebraska provides services to persons with severe/profound mental, behavioral and medical needs, it would be the attitude or philosophy, if you will, of the decision makers. Lou Brown has, perhaps, stated this philosophy best:

> All individuals, regardless of the severity of their handicapping condition, will ultimately live in complex, heterogeneous integrated community settings.

Put simply, if decision makers believe that everyone will be served and integrated in the community, half of the struggle is over. In systems where that attitude is not embraced, I have seen every conceivable artificial barrier thrown up as a block to providing appropriate, integrated services for everyone.

With a philosophy that drives providers to develop services for all persons regardless of the severity of their handicapping condition must come service models which dictate that the more handicapped the individual the smaller the living environment must be. We have found this to be true not only of persons with severe or profound mental retardation but also those individuals who, in addition to their mental retardation, have severe medical or behavioral needs. This is not a minor observation. It is, I believe, one of the most critical factors which will influence the successful integration of persons with severe needs.

In harmony with a sound philosophy and a small living environment must come the consistent effort to tenaciously restrict and/or eliminate the future development of segregated workshop settings. The workshops of today are rapidly becoming a dead end placement for most persons with mental retardation regardless of their functioning level. It is critical to integrate persons so that they can learn real work skills in a real work environment.

Lest there be any doubt, Nebraska certainly does not have all of the answers as to what makes a good, comprehensive, totally integrated system. Like

Wolfensberger, I believe that for every good idea we've come up with, someone else has thought of ten better. This paper is presented as one commentary on things that have worked, and not worked, in Region V, with the hopes that there will be better ideas given back to us, so that we can improve the services offered in Nebraska.

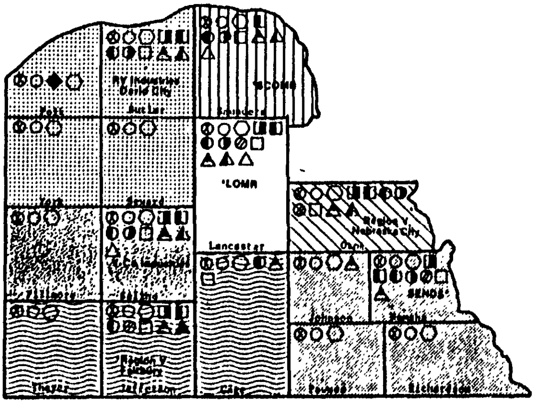
BACKGROUND

There are six mental retardation regions (see cover map) in Nebraska which are controlled by local units of county government. There is one elected county official from each of the counties who sits as a member of the governing board for that particular region. The State Office of Mental Retardation serves as a conduit for funding, and sets and monitors the compliance with rules and regulations for the services delivered by the six regions.

The largest geographic regions have twenty-two counties. The smallest has five. The regional system is accountable to local government, many regulatory bodies and (because of the procedures which have been adopted) most of all to the individuals who are served.

A heavy emphasis has been placed on the involvement of consumers and consumer representatives, as well as professionals from related fields in an advisory capacity.

All of the regions have an area or local system of management which divides the region into smaller units. Control is, therefore, as close to the individual being served as is possible.



SERVICES DURING 1982/83

- ◆ In-Home Training
- ○ Foster/Respite Care Adult Family Homes
- ⊗ Social Services
- ◧ Vocational Workshops
- ◨ Pre-Vocational Services
- ⬡ Extended Family Homes
- ◑ Apartments (supervised)
- ◐ Mini-Group Homes (3-4 persons)
- ⊘ Group Homes (6-8 persons)
- □ Job Placement & Follow-Along
- △ Transportation
- ⚠ Psychological Screening
- △ Speech Therapy
- ▲ Physical Therapy

Each Region V agency is responsible for persons in a specific area. The patterns on the above map indicate the catchment area of each agency.

Region V Mental Retardation Services is comprised of 16 counties and provides or procures work training, residential alternatives and therapeutic support to over 540 persons with mental retardation in community settings. Within this sixteen county region, there are seven comprehensive "area or local programs" (map designates local "catchment" areas) located in seven different counties within the region. Some of the Area Program Directors are responsible for coordinating services for one county, while others plan for up to four counties each. All of the Region V programs are located in rural areas except the one situated in

Lincoln. Without exception, every program serves persons with severe/profound mental retardation, behavioral and medical needs.

THE FAIRBURY PROGRAM

Why Was It Established

As a result of revenue made available by the State of Nebraska to place persons out of the institution and into community based mental retardation regions, Region V submitted a proposal to create a new area program which would serve persons with severe/profound mental retardation. In 1980, when this proposal was submitted, with few exceptions, the individuals remaining at the institution from Region V counties were persons who fell within this range of retardation.

While six other programs existed within the region at that time, all of which served many persons with this same level of retardation, concern over saturating any one community, the desire to expand the capacity of the agency, and the wish to serve other geographic parts of the region dictated the decision to establish a new program site.

How Was Fairbury Chosen

During the three years preceding the establishment of the Fairbury program, Region V had established three new rural programs. That experience, coupled with the specific needs of the persons moving into the program, led us to the conclusion (which continues for new program sites today) that any city chosen as a potential site must possess the following characteristics:

- There must be a community or junior college in or near the city for two reasons:
  1) we need a manpower pool from which to recruit and hire staff, and
  2) we want the individuals who come to this, or any of our programs, to

learn related skills, such as those taught through adult basic education, in the same environment as do other adults their age. We do not want to perpetuate segregation in the community by exclusively providing non-work related skill training in our centers. Consequently, some of the persons served in our programs attend classes through the community college, rather than receiving all of their training through Region V.

* There must be a reasonably comprehensive core of medical staff available in the community, either through a physicians' clinic or hospital. Many of the individuals being considered for the Fairbury program had complicating emotional and medical needs. The idea of transporting individuals who needed routine medical or psychological care an hour to an hour and a half to Lincoln was unacceptable.

* Available real estate for housing, as well as a training site must lend itself to adequately meeting the needs of the proposed core of services and must have the ability to absorb reasonable growth.

* The Chamber of Commerce, Mayor and other community leaders must be willing to assist us in securing sites for both the work site and the houses we would need.

* The city needs to be in a county that was centrally located near persons with mental retardation already identified in various communities who need services now or who will in the near future. While the initial group of persons served were from the institution, we had lists of individuals residing in communities who had applied for services, or who were in the school systems and would need services within the next two to five years. Obviously, consideration had to be given to meeting the needs of those individuals as well.

With those stipulations in mind, two cities were identified as meeting all of the criteria established by the Region.

It is not unusual for towns to "court" prospective businesses or industries, as they are the economic life of a community. A new industry brings new jobs and some new employees. They, in turn, buy or rent houses, purchase clothing and food, pay taxes, support churches and more. It occurred to us that our approach to the establishment of new area programs had, in the past, not been in line with our philosophy or our view of the type of business we really are. Consequently, we changed our approach. Instead of asking or expending large amounts of energy and time in order that we might "convince" communities of what a good "service" we provide (charity model) to a "special" population (pity model), we would:

1) Pick communities that met our established characteristics (listed above);
2) Approach them like any large (our smallest area program has a budget of $400,000) industry and see what <u>they could offer us</u>; and
3) Let them convince our Board that they had the best all-around community for our new work site.

With that "bidding" approach in mind, Regional staff and local ARC representatives approached the Mayor and Chamber of Commerce for each of the cities. We provided information regarding the size of our budget, the number of persons we would employ, the number of facilities we would need, the type of industrial products that we produce and a description of the employees with mental retardation we would train.

In addition, we indicated what level of support we would expect from the city with respect to the identification of potential work and housing site locations, information on any zoning restrictions which might be a problem, and asked that they open doors for us with the medical, industrial and religious community, so that initial conversations could begin. One of the cities had a population of 8,000 the other 4,800.

After all of the information was gathered, representatives from each city came to a meeting of the Region V Governing Board to "bid" on the receipt of the new program. In addition to slide shows and packets of information about each city, the two Mayors presented over 30 letters each, which offered support for the program and requested that their city be chosen as the new work site. Those letters were signed by every doctor, dentist and therapist in their respective cities. In addition, letters were submitted from lawyers, ministers, parents of handicapped persons, judges, colleges, ARCs, Rotary, Jaycees, Kiwanis, Optimists and Lions Clubs, the Department of Labor, fire departments and rescue squads, local welfare offices, public schools, newspapers, Industrial Development Corporations, banks, and so on.

With that information in hand, the Governing Board chose the city of Fairbury, population 4,800. The presentations given by each city were comparable in almost every respect, however, the Fairbury area had more individuals waiting to come into services from both the institution and the community. Current and potential individual need proved to be the deciding factor in favor of the Fairbury location.

One of the exciting things we learned when we established this program was the if prospective community locations are given sufficient information, they will not only welcome a program: they will compete for it. The preliminary work in Fairbury helped the community understand its actual role in our program and set the stage for integrated activities later on.

Characteristics of the Employees

We had learned a good lesson about how to have new communities accept not only the program, but the employees as well. The community expected new workers and a new *industry*. While they knew these workers would be severely and profoundly retarded, the *image they were given was that of the mentally retarded person as a contributing member of the business community*, not as a drain on the social or economic community.

Initially, twelve persons were chosen from the Region V population at the institution to be moved into the new program. In addition to these twelve individuals, three individuals from the community surrounding Fairbury were also served the first year.

Currently, the program serves 25 individuals, 11 males and 14 females. The average age of the individuals served is 36. The average time spent in an institution is 27 years. An abbreviated profile of the current individual characteristics follows:

WORKER CHARACTERISTICS	TOTAL NUMBERS
Level of Mental Retardation	
Mild	2
Moderate	2
Severe	7
Profound	14
Epilepsy	12
On Behavior Modifying Medications	8
Behavioral Outbursts	
0-1 Incident per Month	4
1-2 Incidents per Month	11
Once or More per Week	7
Once or More Daily	3
Self Help	
Independent	10
Verbal Prompts	8
Physical Assistance	5
Does Not Do	2

The preceding information reflects characteristics of individuals after being in the program for one year or more. There have been drastic changes in the abilities of these persons, particularly in the self help and behavioral areas.

The real story rests in the changes seen every day in both the individuals served and the agency itself. Again, the limits of this paper do not allow for detail here, sufficient it to say that the changes have been observable and significant.

Staff Characteristics

After determining who was going to be served and where they were going to receiving the service, we had to decide who the staff would be, and what models we would put into place.

When hiring staff, we looked for characteristics that are valuable in staff working with any group of persons with mental retardation, specifically:

- <u>Experience</u>: The staff hired (vocational and residential) had an average of over three years experience in the field of mental retardation. In addition, we felt that staff must demonstrate skills in the areas of behavior management, environmental control such as multiple scheduling, stimulus control, data collection, multiple/individualized programming, and some staff needed to have skills in the area of manual communication.
- <u>Attitude and Philosophy</u>: One of the most important characteristics we looked for was the attitude that the potential administrative staff had about the individuals whom they would be serving and about working with the public. We did not want someone who believed that it was enough to get people out of the institution, we wanted individuals who would not be satisfied until all of the individuals in the program were socially and vocationally integrated into the community. Individuals who had

good public relations skills and enjoyed that aspect of the job were desirable.

- Creativity: A third characteristic we looked for was a willingness to develop new approaches. We wanted staff to constantly search for ways in which the people served could tap into community resources, and thereby grow and develop beyond the limiting expectations imposed by past history. From the start, we really expected breakthroughs from the Fairbury program.

Service Models

In setting up a framework for delivery of services, the initial inclination was to continue doing what we had been doing elsewhere; namely, work sites and small living environments. To a great extent that is exactly what happened.

Of the 25 individuals placed in this program, six are involved in some off-site work environments. A description of the service models used follows.

Work Site

The work site is located in the semi-industrial section of the City. Contract work from local companies, as well as products which have been designed and marketed by Region V, are used to teach job related skills. Many of the contracts serve as a natural form of advertisement that the persons involved in this industry are working on real jobs and have a real income. However, competitive job placement is the goal for every individual in the program.

Dramatic improvement in skill acquisition has been seen since the contract work began. The work site model is certainly not ideal; however, through the work site model, additional, sometimes more subtle, benefits have occurred for the employees and the agency. A few examples of what individuals are involved in and how that has benefited the employees and the community follow:

- During the 1981/82 fiscal year, 100 pallets were produced by the employees at the shop, and in 1982/83, 4,200 were produced and sold. Naturally, more people have learned the skills necessary to produce a product and more individuals are making money, some for the first time in their lives.
- The shop also recycles aluminum cans. Last year over 2,300,000 cans were recycled, over $20,609 was paid out to persons in the community and over 1,000 persons came into the center. These community customers have had the opportunity to see the real work that the employees are involved in, and interacted with the employees on a "reverse status" basis. That is, the normal community citizen is coming to the center to be given money, vs. the idea that people with mental retardation are only recipients of money from tax payers.
- The most complicated product that this shop produces is braided horse and cattle halters. Over 200 of those units have been produced and sold.

One of the goals of this program is to gradually phase each individual out of the work site and into a competitive placement or a work station in industry. This goal is shared by all of the work sites in the Region. Where can an individual best learn work skills and habits than in a real job? That is the process by which we have all learned our professional skills. We must work toward making the industries and small businesses that already exist in the community our work sites.

- In line with the belief that individuals should not be isolated in work activities centers, some of the training activities take place away from the work site. For example, the program has community contracts for lawn care, carpet cleaning and a news circular route. One individual is placed at Headstart.

Homes

If your child were having difficulty learning in a school classroom of thirty individuals, would you want him/her moved into a class room of sixty? Obviously not. The same holds true for persons with mental retardation of any level or any behavioral or medical need. We have learned that group homes of eight to ten persons are too large. Two or three individuals living together with a staff person makes for a much richer learning environment. It's easier to teach, to control the environment, to integrate with your neighbors, to travel in a car (not a van), to go downtown, and to learn in that environment. The attention individuals require is more readily available if it has to be shared with only one or two other individuals.

Persons with severe behavioral needs, in addition to the severe or profound mental retardation, may need to start with a one-to-one living environment. As individuals adjust to controlling themselves and their environments, one or two roommates may be gradually added, if economically necessary and socially appropriate. As stated earlier, eighteen (18) individuals in the Fairbury work site came from an institution and now live in the small group living homes described below. The total number of individuals living in small group homes is twenty-one (21). Three (3) individuals live with their natural families and one individual lives in an Adult Family Home.

* Small Group Homes: Of the individuals living in group environments, fifteen (15) live in a home with two other roommates. All of the houses are staffed for 1 Full-time Equivalent (FTE) staff weekdays and 1 FTE staff weekends. In addition, part of the stipulations made by the institution, in order for individuals to move into the community, was that Region V would provide overnight awake supervision. That

stipulation was made for any individual who had had a seizure during the past five years, individuals who had to be "specialed" (taken to the toilet or had to be checked frequently), also for some people who were non verbal, or anyone who got up during the middle of the night. <u>In every case</u>, overnight awake staff were phased out of the small group homes after a 30 day period. The phase out was not done arbitrarily, rather, data was recorded and training initiated to eliminate the behaviors identified as necessitating the overnight awake staff.

* Large Group Home: Six of the individuals live in a large group home (six person) which provides 2 FTE staff weekdays and 2 FTE staff weekends. In addition, overnight awake supervision is also being provided and has been for three years. However, it is projected that this staffing pattern will no longer be needed after January, 1984.

* Adult Family Home: One individual lives in an Adult Family Home, which is similar to foster care for children. This alternative is provided with a family in a private home, licensed by the Department of Social Services (Welfare). Region V recruits, trains and monitors the provider.

Quality of Life

No matter what the size or cost of the (service) "model of choice" the most important concern should be the quality of life experienced by each person with mental retardation. When we evaluate our agencies or train our staff, one of the exercises we all participate in is listing those things which make our lives meaningful or good (money, friends, family, lovers, independence, control). We talk in terms of what normal individuals "X" age (as we grow older the sample age goes up) do to have fun, what it means to be a good neighbor, have money and shop where we please. From those lists we talk about how many of these experiences persons with mental retardation participate in on a regular basis. What we are really trying to get to are those components that give our lives quality.

Some of the things we have done to improve the quality of life for individuals in the Fairbury program and other of our programs follow:

- Individuals are involved with the community college in their Adult Basic Education Classes which is seen as a real status builder. The fact that some individuals are interested in going over to the "College" demonstrates the increase in self esteem and confidence many of the employees have gained during a short three year period of time. One of the Region's goals is to <u>spin most or all of the training over to technical, junior or community colleges</u> as work sites phase down and out.
- Some of the employees, when first moving to Fairbury, had never gone shopping or attended a church service. In many cases, behavioral outbursts precluded training during normal "open" hours for merchants or church services. The business and ministerial alliance responded openly and positively. We did the task analysis and program design, they opened their businesses during off hours and held special church services until everyone was integrated into the normal business and church environments. That process took three years, but it is now complete, and no "special" or segregated training takes place in these areas. The only exception will be new individuals who enter the program and who may need this unusually intensive training.
- Leisure activities have also provided <u>many</u> firsts in peoples' lives. For many of the employees the last three years have given them the first opportunity to take regular vacations, catch fish, go to dances or concerts, participate in softball games, see rodeos, the list goes on

and on. The obvious issues with leisure time activities center around frequency, variety, integrated activities and SMALL numbers of persons with mental retardation traveling together.

* As a result of the internal evaluation done on each agency in Region V, a heavy emphasis has been placed on persons with mental retardation being given the opportunity to initiate and/or participate in community service activities. Instead of always expecting the community to give to us, we are expecting our staff and employees to give back to the community. Examples of activities are as varied as what each community does for its own. For example, some communities have held CROP Walks (to raise money for an international relief program and two local gardening projects. In response to the request from the Ministerial Association, the Employee (Client) Advisory Board at Fairbury decided to participate in the fund raising event) and some local employees have participated in them. Others have chosen to adopt a Senator (political action) or adopt a neighbor (elderly contact and call program). Others prefer not to be so formal and do a lot of contact with persons of their choice on their own.

Costs

Fairbury is the second (out of seven programs) most expensive program operated by Region V. That is due, primarily , to the small size of the program and to the needs of the individuals being served there. In order for that to be meaningful at all, some detail is provided as follows:

FAIRBURY AVERAGE PER PERSON COSTS

Service	Costs
Vocational	$ 6,953
Residential	14,879
Transportation	491
Administration	2,636
Social Services	568
Total	$26,039

Conclusions/Recommendations

After describing one experience with the establishment of a program which serves primarily persons with severe/profound mental retardation, I would like to share a few additional recommendations for those of you considering the establishment of similar services. I will try not to duplicate recommendations given in the body of the paper.

1. Serve a Cross Section of Developmental Needs: Develop Staff Expertise and Build Budgets Slowly.

   This is probably one of the most important decisions that can be made with respect to the ultimate capacity of a system. If you take a cross section of individuals with varying characteristics which would include developmental levels, medical and behavioral needs, technology spreads and budgets grow in a steady, competent fashion. For example, if two individuals with severe behavioral disorders are placed in an agency one year, a core of staff (let's say four) can be trained to work with and support those individuals as they learn and adjust to community living. At the same time, staff will develop further confidence and skills as they design programs and adapt environments intended to enhance the success of the persons with whom they work. The following year, you could take an additional four individuals with behavioral needs as the original core of four staff persons train eight additional staff to work with those new persons. As time passes, individuals who were once seen as extremely difficult to serve become a routine challenge to staff who are confident of their ability to adapt behaviors. Technology spreads as individuals who were once seen as "residual institutional populations" become integrated into the community.

Another advantage of taking individuals with varying needs is that budgets will grow steadly over time rather than peaking when more "difficult" populations are finally served. There is no doubt that some individuals will need more intensive staffing patterns and therefore cost more than other, less involved persons. If, over years, you build those staffing costs into your budget, people with mental retardation will not have to bear the burden of "being too expensive to serve". Averaging costs over numbers of individuals with varying needs, generally, makes for a cost that can be justified to boards and legislators. Whereas, averaging costs over a group of individuals who have only high needs seems to stimulate calls for conservative fiscal restraint and larger institutions for "those" people. It is our responsibility, as administrators, to act responsibly so that groups of individuals don't get set up to fail on fiscal issues they can not possibly control.

II. Integrated Environments and Role Models are Critical.

I would state clearly that clustering persons with like needs, as we did in Fairbury, is NOT the way it should be done. A cross section of developmental needs should not only be taken but should be placed together. Segregation of any kind, should be avoided. That goes for segregating persons with high needs from persons with low needs. Role models are lost, inappropriate behaviors are shared and modeled.

III. Use the Changing Technology with the explosion in computer technology and the advances in bio-engineering, great strides are being made in the area of services to persons with severe/profound mental and physical disorders. There are many "tools" that can be used today to make learning and improvement much easier for both the worker and the staff. We would be remiss if we did not take advantage of technological advances.

IV. Consistent, Structured Programming is a must. Programs will have to be designed and run based on seconds not minutes. The task analysis will have to be broken down into much smaller steps. Thought will have to be given to the jigs used to compensate for severe physical impairments. The rest of the principles appear to be the same.

V. Use Community Resources:

Rather than restate what has already been gone over in the paper, I would summarize by stating that the vision you have of what you are will, to a large extent, be embraced by the community. If you view yourself as an industry, then use community organizations, mayors and city council's as industry would and let them do the ground work for you if your are just coming into that community.

If you are already established, use community organizations as a means of doing some public education, employee training, and a group from which support can be mustered.

Community colleges, technical colleges, and universities are a tremendous resource for us and may, someday, become the training sites as our workshops close down.

Medical Services in many instances here in Nebraska have improved in the rural communities where we have established programs. Where some communities did not have access to anaesthesiologist, we have joined with the local medical community to bring in such a service/person. The entire area benefits.

Use the Media like anyone interested in enhancing the image of his business would. As you elevate the status of your business, you also elevate the status of your staff and employees. Give the media legitimate stories, geared to meet your image (industry) or to tell your story (training workers) or to get your employees jobs outside of your work sites.

As you develop or continue programs for persons with severe/profound mental retardation and come to your own conclusions please share them with us!

Senator DURENBERGER. Thank you very much.

John?

Senator CHAFEE. Yes.

Ms. Rucker, the Touche-Ross study you mentioned, didn't Mrs. Crawford mention that same study?

Ms. RUCKER. Yes.

Senator CHAFEE. And didn't she come to an opposite conclusion?

Ms. RUCKER. I am not sure that she came to an opposite conclusion, because she was cut off. But I have the report here.

Senator CHAFEE. I thought she said it shows that it was more expensive. But I will look that up.

Ms. RUCKER. What it compared were the six mental retardation regions in Nebraska, as well as the institutions. And I have the report here and will certainly leave it.

Senator CHAFEE. One of the things I was interested in in your testimony was that you cover those in rural and sparsely populated communities as well. Could you touch on that briefly? Because you mentioned, first of all, that you deal with those who are considered "severely retarded," and we have had some testimony I think from Mr. Napolitano or someone here—I don't know exactly who—that indicated that in these rural settings it would be more difficult. How do you handle that, the medical problem?

Ms. RUCKER. For persons with what is now a collective term called the medically fragile, you will generally find those persons in Nebraska in what we call foster care or adult family homes; that is, one individual, if a child, is placed in foster care. If he or she is an adult, they are placed in foster care in what's called an adult family home. One or two, usually one if they are medically fragile, placed in a family.

What we have found is that for persons who have gastrostomies—that is, they are fed through a tube in the stomach—or they need some shallow suctioning, or they have severe hydrocephalus, spina bifida, whatever, that the needs that those individuals have are readily taken care of under medical supervision by trained staff. If someone has to have deep shallowing, then obviously the foster family has a registered nurse in that foster family. But we have placed individuals with severe medical needs into small families, single families, and have provided the training and the monitoring necessary to maintain those individuals.

If they are children, they are going to school during the day. If they are adults, they are in our programs, perhaps for no more than 2 hours, but they are out of the house during the day.

Senator CHAFEE. Thank you.

Mr. Napolitano, you were mentioning about the Bethesda Lutheran Home in Watertown. What do you do there about the workshops, the occupations that the residents have? How do you handle that? Do they work right there on the place, or how is that done?

Mr. NAPOLITANO. What we have is a whole stratified system of workers. In other words, those that can work in the job sites at the place in a normal job are paid in accordance with the Federal regulations, a percentage commensurate with the commensurate wage of that job. For instance, if a laundry worker is 80-percent proficient of a regular employee he gets 80 percent of whatever that employee is being paid.

Senator CHAFEE. Do any of them work off the premises?

Mr. NAPOLITANO. Yes, there are some, but there is minimal at that station. Now, in all of the group homes, of course, they all go to workshop. But in the home campus, then they go down—we have an active workshop where they produce in what is more of an educational sphere, where they are learning to do tasks, and so on.

Senator CHAFEE. Why do you have the group homes? Is that just a matter of choice, or is there some benefit from it?

Mr. NAPOLITANO. We basically are not quarreling with the concept proposed by the bill. We, on our own, have developed the group homes. In fact, we have some in Michigan and other States. We feel that that is one of the points to go. However, we feel strongly that the institution plays a role in that, in training.

Now, when we get a request for an admission, if that resident is considered to be high level, we will not admit that resident to the Watertown campus. Now, we may admit him or her to one of our group homes, if we have one in that particular State. We only admit the severe and profound, and we work very diligently to try and make placement, if we can, to a less restrictive setting.

The only thing we are struggling here with is that we feel we developed a great deal of expertise over an 80-year period. We feel we have an outstanding staff, and what this bill says in essence, although it doesn't directly say that, is that withdrawal of funds in the long term would tend to diminish that or in essence wipe it out, because our constituency is now already developing a support base of 50 percent. And to task them to double that is very difficult. I mean, we will face that at the time, but we are here because we feel we have a service to offer, and we feel we have demonstrated that. And we feel we are in the community sphere by moving in the same direction.

All we are saying is we feel the institution or the large facility with an excellent program has a place in the whole strata of providing services.

Senator CHAFEE. Let me ask you this question and this question will be particularly directed to you and to Mr. Walsh.

Suppose we had legislation that provided the funding would go for a resident at a larger institution for only a limited period of time. In other words, the thrust of much of the testimony here is that no matter how severely retarded an individual is—let's just take retarded, or multiple handicapped—that being in a smaller setting is better in the long run for that individual, that that individual reaches his or her greatest potential—and we have had testimony from Ms. Rucker and a whole series of other witnesses on that subject—but at the same time it may well be that an individual has to go through some kind of training, if you would, adjustment, before he or she would acquire the abilities to do well in a smaller setting. Now, what about that?

In other words, I guess the question really is: Is it your belief that there are some individuals—and judging from your figures I suspect that from what you have indicated you think that 50 percent perhaps of the individuals really should remain permanently in a larger institution, and let's say over 300.

Mr. NAPOLITANO. I wouldn't use those figures to that extent. We are working through a phasing down. What I did say is that a number of individuals stressed here that when they were questioned more tightly that they then began to admit that there is going to be a residual. And I guess what we are talking about is, there is going to be certain cases in the "medically fragile," the "behavioral" and in the "severe and profound" that are not going to fit these small ideal settings.

Senator CHAFFF. But some people aren't prepared to admit that. Ms. Rucker isn't prepared to admit that. Nor am I.

Mr. NAPOLITANO. All right. Well, we have residents where we design carts to get them around, to get them the program, to get them outside. Now, we know many of the homes—and I don't care how you design them—are not going to be able to handle this. We know this.

We know, too, that a lot of claims have been made. And I am taking some names down, because I am going to visit some of these sites, and I want to see some of these claims that are made here today. It is very easy to make these claims—"Oh, we've got a miraculous recovery," "Oh, they are out there 2 hours," and "They are out." I want to see that. I want to see their turnover. I want to see the burnout. OK? In a sense, I'm from Missouri and I'm not going to accept everything that is said here.

Senator CHAFEE. All right. Mr. Walsh wants his time.

Mr. WALSH. It was my understanding that the bill does now provide for something like a 2-year maximum in an institution. "Institution" though is described as any place larger than 10. I objected to that before, and I would still object to labeling Mount Olivet Rolling Acres with its 7-year residents in groups of five, in separated houses, on 23 acres on the lake, supported by a congregation of 11,000 members, as an institution. Certainly, I don't think there are going to be a set number of years—2 years, 4 years, 5 years—there has to be some kind of variable. I don't think you will find anyone in this room who doesn't want mentally retarded people in the best place for them, be it for 1, or for 25, or for 50, or 75. That is not the argument. However, it is impractical to say 10 is the limit.

Senator **Chafee.** Well, let me ask you this question:

It seems to me that what you are saying is that no one knows. But if we accept the philosophy—well, I guess you are not prepared to accept it—that a person will reach his or her potential to the greatest degree in a small setting, then how are you going to press the States to do this? Under the present system, as you have heard in a lot of testimony, there is bias all down through the funding system is to favor the institution. You have heard that from South Dakota; you have heard it from other witnesses as well.

Now, we are thinking of changing that bias. But you are saying, "Leave it up to us to decide who are the providers, what is the best." Is that what your theme is?

Mr. **Walsh.** I don't think so. I don't think all of the providers necessarily know what is best, because I think some of the providers get locked into—even though we are nonprofit—sort of a proprietary attitude, also.

But it is possible to fund programs in Minnesota with medical assistance for six residents, and we have many of them. So it isn't locked into any one number; there is a variance. As a matter of fact, I think medical assistance can fund a facility for one; so the options are available now to go from one on up to any number.

Senator **Chafee.** Well, thank you all very much for coming. This has been helpful, and we appreciate it.

Senator **Durenberger.** Let me ask just one question before you leave, and I want to give John the opportunity to explore more of these issues.

I need to ask Lyn and Jon Nelson, then, to react to what Jerry Walsh just said about what's wrong with 70 people in 5-person cottages on 22 acres, as opposed to whatever the Chafee bill says. Excuse me, do you want to clarify that?

Mr. **Walsh.** In groups of five, in separated living units on 23 acres.

Senator **Durenberger.** Well, suppose an apartment building were 20 units, and you are raising families in an apartment building with 20 units, and you have a little bit of grass down there, and a whole lot of asphalt. I mean, there are millions and millions of people in America being raised that way today. And I am not advocating that as living conditions—I mean, we've got it all over the Twin Cities. We are all going up, and we are raising our children in elevators. [Laughter.]

But, Lyn, you very clearly said that at the Mount Olivet—and I keep getting bothered by "Is six the right number?" "Is 10 the right number," or whatever it is. I mean, I can't play Solomon. You said the IQ's are going to go up if we buy into six or some very small number, and it is going to go down at Mount Olivet—or where is it going to go down? Is it going to go down at Mount Olivet? I mean, specifically. I am really trying to pin this down. I can see the old Minnesota that I remembered when Jerry and others were getting very involved, and we were literally warehousing people. I can understand IQ's going down in that setting.

I am trying to figure out in today's setting, just using Mount Olivet as an example, is that a level-IQ facility, do you suppose? [Laughter.]

Or is that a going-down IQ facility?

Ms. **Rucker**. Well, since my attorney isn't here to represent me——

[Laughter.]

Let me say that the study I was referencing, which is here in the attached journal, dealt specifically with the institution in Nebraska, comparing the IQ's of the region V residents in the institution with region V residents living in the community. And what that study showed clearly, particularly--and I can show you, it is attached to my testimony—for the severely retarded population, that those who were living in the institution, 7 percent of their IQ's increased, while 62 percent of the IQ's decreased. In the community, those who were living in the community, 71 percent of their IQ's increased, while 3.2 percent of the IQ's decreased. And that's all I can say. I can't talk about Mount Olivet, and I can't talk about Michigan. I can say that the methodology that was used here can be employed at other places.

In terms of your initial question dealing with, would a five-person group home on a campus of *x* -hundreds of persons be any different than a five-person group home in the community, I would say absolutely, for the following reasons——

Senator **Durenberger**. In outcome, now. Tell us in outcome. I know it is physically different.

Ms. **Rucker**. Specifically in outcome. Obviously it is physically different.

Let me use an analogy. I don't intend for it to be flip but I can relate to it, and that is, if I were to associate with only blond-haired blue-eyed Swedes, I wouldn't be a very well-rounded person. I might be more promiscuous, but I wouldn't be very well rounded. [Laughter.]

The analogy holds because of the misconceptions that we have about groups of people. And if you have groups of people only mimicking deviant behaviors, then you will get a modeling of other deviant behaviors. If you have a child who is in a classroom and doing poorly, you don't want that child put in a larger classroom; you want that child put in a smaller classroom where they will get more attention, not less. If you have people with behavior problems, you don't put them with other people who have behavior problems, because then they start imitating each other's behavior problems.

What I am saying is, Yes, it makes a difference, Yes, people need to be integrated with normal peer models. You don't intern in a play hospital; you don't learn behaviors in a play or artificial environment—you have to learn it in the real world. And that's why I think the outcomes would be different.

Senator **Durenberger**. I don't want to be argumentative about it, because we are starting to run out of time. But it strikes me that, for the same reason that I oppose the nine-digit ZIP Code, because I know we can get mail to people with five or four and we don't need nine, I really was more concerned about getting mail to people than I was about how many numbers we use.

So I can't quite understand why John in his bill does not prescribe, on the best knowledge available to us today, describe the outcome desired and the kinds of specifications in setting that we know produce that kind of outcome.

Ms. RUCKER. The danger in that, Senator, is, if he were to say, for example—and I don't know how you would structure your outcome. But one of the difficulties becomes "Where are you going to draw the line?" If a person with whatever level of mental retardation in your opinion has to progress from not being able to eat at all to being able to eat with a knife, fork, and spoon, where I believe that a person who cannot eat by themselves at all shows significant progress if they can pick up a spoon, where do we draw the line? Do we draw the line at an IQ of 40?

Senator DURENBERGER. No, we want to keep pushing the line out beyond our last piece of knowledge, I assume.

Ms. RUCKER. Right. So I am saying if you start prescribing outcomes in Federal legislation, I think perhaps it is too much on target. Rather, you set the broad public policy and expect that technology will change so quickly that, were you to put that in legislation, it would be outmoded a month later.

Senator CHAFEE. I visited the Clara Dorn residence today, Mr. Walsh, and there you see the example of pressing, urging an individual to reach his best. That is a temporary residence in which the flow is outward, and they train them. Well, you know more about it than I do, but it was very impressive to see a young man there who, not in some large rural setting, not in a large institution, who takes the bus each day to his job and earns his living, and the goal there is to get him out even into a smaller group. I found that very, very thrilling.

Now, there is no question in my judgment that that person, if he remained in a large institution—and you can quarrel over what an "institution"is. I guess that is what we are striving to do. And he had great self satisfaction in his career, which was taking the bus to be a dishwasher at a local facility. And it wasn't a facility solely for the mentally retarded. I mean, it wasn't a "workshop." It was a facility right here in Minneapolis.

Senator DURENBERGER. Thank you all very much. We appreciate your help a great deal.

The last panel is Dean Thomas, parent from Minneapolis; Bette Rosse, a parent from Minneapolis; Bob Jirik, a self-advocate from St. Paul; and Daryl Pederson, a self-advocate from Minneapolis.

All right. Remember we have that microphone there that gets to the back of the room where there are still a few folks left.

Dean, you are first on our list. Thank you very much for being here.

STATEMENT BY DEAN THOMAS, PARENT, MINNEAPOLIS, MN

Mr. THOMAS. Thank you, David. Thank you, Senator Durenberger for being here, and thank you, Senator Chafee, for including me here.

You have heard a great deal of testimony today; the hour is getting late, but I would like to recap this from a little different point of view than perhaps has been represented by the speakers today.

My name being Dean Thomas, having a son that is profoundly retarded who is presently in the Clara Bow State Hospital, explains my bias. I don't, however, really believe that I am defending that bias particularly, as I hear the various testimonies about conflicting types of things that are being presented to you here today.

I do believe, however, that in my experience in the American free enterprise system, and spending some 35 years in major business, that were I faced with the same kind of a problem that this is presenting to the taxpayers of the United States and to the board members of a major company, one thing that seems to be prevalent in my mind is that I would put this into some kind of controlled marketing study where I could measure these variables.

Let me mention a variable which I think is being used here in an attempt to prove two sides of an issue. First of all, if you take a retarded citizen who has low functioning power, you will usually find him a member of either a large institution or a State institution, simply because the smaller community won't accept him

I just went through an experience of this with a profoundly retarded child in trying to place him in the community. And we got 15 rejections. The reason we got those rejections is, he cannot perform in the kind of small community that these people are conducting presently. So, as you heard people say the IQ "of this small group, 7 to 15," they are selected individuals of high-performing retarded types of people who naturally have higher IQ's. The severely retarded person not being able to qualify in that will find himself in a different type of institution, and I think that is one kind of a variable.

But I do believe with the kind of conflicting information that you must have heard all over the United States with people presenting legitimate data—and let me say, in most pieces of marketing research you can prove almost anything you want to prove, whether you want to protect your job as a runner of an institution or whether you want to protect your job in a State institution. That can be done through research.

And therefore, I really urge that what you do is establish a control, that you go into various communities and establish controlled units that are comparable one to the other, and you measure one control against another control of classified people who can give you specific data, relative data that compares one to the other.

If you go to the California situation—a disaster. I happen to be privy to some information at Michigan from some friends who have retarded friends there, and the trauma and the chaos that their lives went through in Michigan—I am surprised that a State would put anyone through that kind of traumatic experience—which you have to do if you are going to close the larger institutions.

I spent 18 years at the Brown School, with my son at the Brown School, a private institution in Texas, and I became close to a man named Dr. Charles Cleland, who in my estimation is perhaps one of the great thinkers in terms of the retarded people. He has written six books. And I think that would be one kind of man who could set up control for you in that development. And, incidentally, I think Texas is doing an excellent job in going both ways, with both the institutions, the waivered services, the small communities, and everything that fits the care and welfare of the people.

I think there are really four things you are driving for. At least in my estimation they would be the four primary points of your investigation:

First, I think, Senator Chafee, you have expressed this already. You want exceptional care, regardless of anything else. That is the first priority—exceptional care for the retarded people is probably the first priority, and I don't think there is anyone in this room who would argue with that particular statement.

But with that exceptional care, you also have to employ a cost efficiency, a cost efficiency that compares one unit to another unit in terms of equal units, so that you can get a measurement of exactly what cost efficiency is in this business.

Next, there is the difference between the classifications of retardation. It runs a gamut from highly performing people down to a very low level of vegetable who can do nothing but just lie there. And I think here again you have to classify this kind of thing and measure your test against the classifications of retardation, the service to that retardation.

Now, last I think there is a point that perhaps hasn't been made well enough, and that's what can any one of these communities do that is synergistic to the community need beyond the retarded situation? We in Fairvo believe that we are running a very separate kind of thing that is small cottages with small groups of people. We are almost equal to the Mount Olivet situation; we aren't quite there—Jerry's on our board—but we are trying to service in a decentralized setting the various classifications of retarded people. But we believe that we can service other parts of that community. We think that Fairvo, with its expertise—and when I speak of "expertise", I happen to have a book here by Charles Cleland that is just an instruction book for the care of retarded people. If you read that book, and I am a college-educated person who graduated from the University of Michigan, I have difficulty in it. It is a very difficult subject to learn.

My point, simply, is that it takes a great deal of expertise to care for these people. With that expertise you can also care for other people who have traumatic situations that are not in the "retarded" classification. Depression is a great problem of our society today, and there are other great psychological problems that are difficult in our societies. You can use the wealth of knowledge of the large institutions to help service the community. And I think that is a plus that perhaps hasn't been mentioned in the various testimonies.

Again, time is getting late, but I would like to say that I admire your courage, Senator. I think you are doing a tremendous job in investigating the tremendous part of the retarded situation, because this has been a subject that really wasn't discussed 30 years ago. I do, however, believe deeply that this is a very serious problem, a great serious problem for the taxpayers of the United States, and I really hope that you will take all the testimony, et cetera, and set yourself up a marketing examination that lets you compare apples to apples and oranges to oranges, not the controversy.

Senator DURENBERGER. Thank you, Dean, very much Bette?

[Mr. Thomas's written testimony follows:]

TESTIMONY OF DEAN F. THOMAS ON COMMUNITY AND FAMILY LIVING AMENDMENT OF 1983—S. 2053

My basis of contest are as follows:

In opposition to S.2053

I. The basic assumption put forth in the proposed S.2053 of shifting Medicaid funds for the mentally handicapped from institutions to smaller (15 population) community based settings is fundamentally wrong.

Its recommendation fails totally to recognize the severity of the retarded long term care issue in terms of:

> The multitude of problems and opportunities associated with adequate care for the vast range of human deficiencies present in the retarded and handicapped population.

I.1 As with all human beings, there is no "oneness" to the retarded population, but a complicated array of malfunction within an already complicated structure of human existence with which S.2053 cannot cope.

I.2 The demanding expertise and physical plant required for adequate care and safety of the severely retarded.

I.3 The vital role that already exists in the state of Minnesota, and other states, of the larger community facilities and the state institution.

I.4 The chaotic confusion that would result within the neighborhood communities should S.2053 become law, forcing the closing of today's only adequate care for the severely retarded.

I.5 The tremendous opportunity now in place to restructure the regulations that limit the larger facilities and the state institution to be cost effective.

I.6 The human suffering of the severely retarded and their relatives, as the forced impact of S.2053 transfer of the severely retarded to the inadequate community "small" unit.

I.7 The cost to the taxpayer for a mass market change to S.2053 that is clearly inadequate to serve the complicated problems of long term care for the severely retarded. No risk of this magnitude should even be considered without a fully structured marketing plan in which all the variables have been carefully examined. This has not been done in the case of S.2053.

I appreciate very much, Senator Durenberger and subcommittee members, for the opportunity to testify. The very fact this hearing exists, is extremely gratifying, as it deals with a subject which, as little as ten years ago, was not eligible for public debate with understanding.

My prejudice for being here is in opposition to S.2053, which in my estimation is a suggested bill which attempts to capitalize on the tremendous cost of Medicaid at the expense of the retarded community's inability to speak for themselves. Whether this is a purposeful intent, or a gross error in judgment, is not my concern. What is my concern, is the fact that S.2053 is a dangerous innovation that at best would benefit only a few of the high functioning retarded population, at a dangerous risk to the severely retarded, the large exceptional care facility, the state institution and the public.

My basis of contest are as follows:

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Recommendations

The documentation of S.2053 to deal with each of these seven issues does not exist, and particularly with the state of Minnesota. Its "Iron Pants" conclusions are empty predictions that attempt to say cheaper costs, which means nothing, if true. What does mean something is quality of care at cost effective expense. The state of Minnesota has, in place, a system of retarded care that ranks with the best. Certainly it can improve and must, but to destroy what exists without a state effort to build on what it has would be a violation to the taxpayers of Minnesota and to all those who pay taxes throughout the United States.

My plea is to provide legislation that allows both the private and public system of Minnesota to remain. Improve from this base with Medicaid that rewards this efficiency. Certainly with guidelines, but not "Iron Pants" so typical of Federal legislation. Leave the incentive with the people of Minnesota who understand its ability and success todate. The fabric is here and functioning.

I am an Advisory Board member at Faribault State Hospital and I can prove my statements of exceptional care with opportunities to become outstanding in the areas of:

1. Exceptional care
2. Cost efficient
3. Severely retarded expertise
4. Expanded services which are synergistic to the community needs

Again, I appreciate submitting my testimony. I can only add that I am an involved parent. Certainly bias to my son, but you cannot be an involved parent without understanding the tremendous difficulty the retarded population has in telling their story of need and want.

"As each star in the heavens differ in brightness, so do the children of God."

Sincerely,

Dean F. Thomas

Dean F. Thomas

DFT:mb

STATEMENT OF BETTE J. ROSSE, PARENT, MINNEAPOLIS, MN

Ms. ROSSE. Senator Durenberger, Senator Chafee.

My name is Bette Rosse, and I'm what many of those in today's audience call "a parent," which means not only that I have a child but that I have a mentally retarded child. My only son, whose name is Scott, is severely mentally retarded, but he has further fallen into a loosely defined class of disabled people who have previously been marked as the kind who should spend their entire lives in the confines of the State hospital of Minnesota. A previous testifier called it the residual.

Specifically, Scott is behaviorally disordered by a second disability, autism, such that there exists an ever present danger of aggression or self-injurious behavior when he is in an environment which is unresponsive to his individualized needs.

Six years ago we formed a small, nonprofit group including parents who were desperately concerned about the fact that their sons or daughters were deteriorating in large institutions and showing no enjoyment of life there. Our purpose was to create a service that would prove that severely disabled adults like our sons and daughters could have a future of real growth and could have real dignity in community-based services.

Many, even some parents and professionals, expected us to fail. They thought such severely disabled people, "the residual," could not be served in the community. And they were wrong.

From our efforts, residential services arose to serve 15 behaviorally difficult adults, many of whom came in desperate condition from large institutions or hospitals. After nearly 2 years, there is unequivocal evidence that all 15 are developing new skills and increasing their enjoyment of life.

Mentally retarded people can receive specialized services within the four walls of an institution or, at least equally well, within the four walls of a small community residence.

But I would like to focus on the critical issues of quality of that service and protection from neglect and abuse.

The first advantage of a community residence for quality and protection is that all residents are required to attend programs and receive services outside of their residential service. For our severely disabled, especially nonverbal sons and daughters, this involvement of several agencies provides a good daily check on the quality of care that each place is providing. Tragically, neglect and abuse can occur to the vulnerable anywhere; but in the community, with several agencies involved, it is far more likely to be detected and corrected.

A second advantage of community residences for quality and protection is that of independent licensing. In our Minnesota, the department of human services both licenses and operates the State institutions, but community residences are operated privately and licensed by the State. Separating the responsibilities for operating and licensing, obviously, strengthens the checks that are available to ensure quality and protection.

A third advantage of the community is that many smaller residences can be closer to families and easier for families to visit, so that the quality and safety of care are more frequently monitored by those who care most.

But let me tell you about a fourth form of quality and safety protection that I learned about through our son's community residence. Small community residences are not isolated; they are a part of their communities and a part of their neighborhoods.

At my son's residence, the manager of a nearby convenience store stopped over to give a donation collected by his employees for the use of our residents. The employees had noticed these folks when they, accompanied by staff members, purchased items at the nearby store, and the employees wanted to do something to help out.

Then the director of the city parks stopped by; his staff had noticed that our adult residents and staff frequented a nearby park, and he wanted to know what equipment he might add for the use of the disabled folks. And nearby residents offered their services as volunteers.

While these kindnesses were greatly appreciated, it goes beyond help and appreciation. I know in my heart that American neighbors like these would not tolerate the unconscionable abuses which are history in large State hospitals because of their isolation.

The hearing announcement asked that testimony address the question: How can we provide the best care in the best way? I offer the answer that care can be provided in the four walls of an institution or the four walls of a small community residence, but the critical issues of the quality of that care and protection from abuse and neglect demand small community residences.

I have one brief final point. There is an issue of morality which must be stated. Large institutions are not like our small community group homes or like any of the homes that any of us here live in. There are only two times in our entire lives that those of us with choices live in large congregate settings. Briefly in our college years, and perhaps again in Army years—again, briefly, because even the Army knows that people who have other choices will not stay long in a system which uses large congregate housing. The moral issue? We who are the able majority cannot choose a style of living for the vulnerable minority—mentally retarded people—that none of us ever chooses for him or herself. As a matter of morality, of fairness, of human and civil rights, we cannot choose by our funding large congregate living arrangements for the vulnerable mentally retarded people among us.

S. 2053 is needed as legislation now.

Thank you.

Senator DURENBERGER. Thank you very much, Bette.

Bob?

[Ms. Rosse's written testimony follows:]

-- SUMMARY COVER PAGE --

Testimony of:

Bette Rosse
3725-47th Avenue South
Minneapolis, Minnesota 55406

Phone: 612-724-9552 or 612-827-5641

Given:

on August 13, 1984,
before the United States Senate Finance Committee's
Subcommittee on Health,
Minneapolis, Minnesota

Summary of Principal Points:

(1) Introductory comments are provided.

(2) Locating small residences throughout each state allows many, many more mentally retarded people to maintain close contact with their families than does the use of large facilities.

(3) Well-trained, competent, enthusiastic staff members are readily available to small community residences.

(4) <u>All</u> mentally retarded people can live in small, community residences -- any needed services which are provided within the four walls of a large institution can be equally well provided within the four walls of a small community residence.

(5) Using small community residences allows mentally retarded people to receive the special help, support and quality assurance which neighbors provide to neighbors.

(6) Large, congregate institutions are unacceptable for governmental support as residences for mentally retarded people since other people -- those with choices -- do not <u>ever</u> choose to live in such settings.

I would like to introduce myself to you.

My name is Bette Rosse. I'm what many of you in today's audience call "a parent", which means not only that I have a child but that I have a mentally retarded child.

My only son, Scott, is now a young man. He is severely retarded, and he is also autistic, a second handicapping condition which means that in addition to all of the limitations of mental retardation, he also has profound communication impairments and he has severe behavioral problems -- aggression and self-injurious behavior. In order to lead his life fully, and to develop to his full potential, and to enjoy life, he has needed and, since there exists no cure for his condition, shall probably always need a lot of specialized services.

Six years ago we were contacted four families who had adult sons older than our Scott, and whose sons lived in state institutions. All four families were desperate, because their sons were deteriorating badly and at least one was in immediate danger of death through failure to thrive. Certainly none were showing evidence of enjoyment of life in those large, isolated living environments, and the families were eager -- maybe desperate is a better word -- to find another living situation for their sons.

Using all of our professional expertise, and all of our concern as parents, we began to design a Community residence and a program which would meet the needs of all of these desperately disabled people, that would provide them with care and supervision, but also with increased family contact, community involvement, and the chance they needed to grow and develop and acquire new skills and enjoy life.

Now both pride and satisfaction overwhelm me as I tell you that after a lot of hard work, my husband and I and other members of our non-profit corporation opened a new community group home named Shingle Creek Option. Our son and other sons and daughters went to live at Shingle Creek Option.

As we designed Shingle Creek Option, we knew we wanted it in the community, near all of the families whose sons and daughters were to live there. We wanted to be able to visit our sons and daughters easily and frequently, and to keep them a part of our lives and to keep us in their lives, just the way things work out with our other sons and daughters.

I must digress here to point out that my son, and others like him, may have lots and lots of problems and they may lack a lot of skills, but they are still wonderful people, and precious sons and daughters. It does describe my Scott to say that he is severely retarded, and that he can exhibit certain aggressive behaviors, and that his self-injurious behavior is a real problem, but it also describes him to say that he's a good-looking young man who enjoys music and drawing and bicycling and cooking, and he's beginning to enjoy swimming.

All of us who worked on Shingle Creek Option knew that our potential residents had substantial needs for very specialized service. We were told by both our County and State personnel that such severely disabled people had not previously been moved out of state institutions and into the community. But we believed that our sons and daughters could be served well in the community. We saw institutions as four walls within which services are provided, and we felt these essential services could be provided within the four walls of a state institution or, at least equally well, within the four walls of a small, Community residence.

Fortunately, for the well being of the mentally retarded people we have the privilege of serving at Shingle Creek Option, we were indeed correct that all essential services can be provided in small settings.

We further believed that we could hire competent people to care for our sons and daughters and others at Shingle Creek Option, in the community.

And we have been able to provide a sensitive, totally competent service, fulfilling a dream that some still say is impossible! The atmosphere is cozy, homey, and gentle, and the quality of interaction between staff and resident is extraordinary, and all needed services are provided competently. Our residents -- each and every one -- are developing new skills which permit them to both participate constructively and to enjoy life. They are each continuing to grow -- as we knew they could -- if given just half a chance.

Those services which we have associated with the four walls of an institution can be moved to the four walls of a small Community residence, where each mentally retarded person can additionally live near family and in a small normalized setting.

My Scott's Shingle Creek Option is small, and in the Community, competently staffed, and located so that family involvement is encouraged. But more than that happens in the Community.

I'd like to focus for a moment on quality of service and freedom of the residents from neglect and abuse -- the critical issues in any service to the severely disabled among us.

A first advantage of a Community residence for quality and safety is that all residents are required to attend day programs which are away from their residential service, and under the direction of another agency. For some, including my son, the bus service back and forth is even provided by a third agency. For our severely disabled, non-verbal sons and daughters and friends and clients, this involvement of several agencies provides a good, daily check on the quality of care that each place is providing. Tragically, neglect and abuse can occur to the vulnerable anywhere, but with several agencies involved, it is far more likely to be detected and reported and corrected in the multi-agency system which exists only in the Community.

A second form of protection for these severely disabled individuals also exists only in our community residences -- that of independent licensing. In Minnesota, the Department of Human Services both licenses and operates the State institutions, but Community residences are operated privately and licensed by the State. Separating the responsibilities for operating and licensing obviously strengthens the checks that are available to ensure quality and safety.

A third form of protection in our Community is that many smaller residences can be closer to families and can involve families, so that the quality and safety of care are more frequently monitored by those who care most.

But let me tell you about a fourth form of quality and safety protection you may not have thought about before, and that I only learned about through Shingle Creek Option:

Small Community residences are not isolated -- they are a part of their communities and neighborhoods. In just the two years Shingle Creek Option has been in operation, the Manager of the nearby convenience store stopped over to give us a donation collected by his employees for the use of our residents -- the employees had noticed our folks when they, accompanied by staff members, purchased items at this nearby store, and they wanted to do something to help out. Another time, the director of the city parks stopped by -- his staff had noticed that our adult residents and staff frequented a nearby park, and he wanted to know what equipment he might add to increase the enjoyment of the folks who live at Shingle Creek Option. And the elderly residents at a nearby town house complex wrote to offer their services as volunteers. Of course, all of these kindnesses were greatly appreciated. But it goes beyond help and appreciation. These people, our neighbors, cared enough to notice our residents, and to find out where they were from, and to think about how they could help, and to then provide the help -- then obviously these people, our neighbors, would also care enough so that if our residents were not properly cared for, they would figure out who to report that to. Being a part of a Community, being a neighbor and having neighbors means that there will be a check on quality and safety that is sincere and continuous and ongoing. To restate the fourth Community protection for quality and safety --I learned that the community, where small residences are neighbors and have neighbors, has a strength that will provide real protection to mentally retarded people now and in the future, the strength of many, many people watching and caring and doing, the strength which comes from being a neighbor and having neighbors, which large isolated institutions have never developed because their size isolates them.

The Hearing Announcement asked that testimony address the question "how can we provide the best care in the best way?"

I offer the answer that care can be provided in the four walls of an institution or a small Community residence, but the issues of the quality and safety of that care demand small Community residences.

I have one final point that I offer for your consideration:

There remains no question that all mentally retarded people can be served in small Community residences -- we know it can be done. We know that the critical issues of quality of care and freedom from neglect and abuse can be better addressed in the Community, with State licensing separate from operation.

But there is a final issue of morality which must be stated.

Large institutions, either State or those in the community are not like our small Community group homes, and they are not like the homes you and I -- any of us here --live in.

I can be sure that you and I -- all of us here -- undoubtably live in very different ways, in very different homes. We have single family homes, large and small; and live in apartments; we live in lake homes; we live in town houses; we live in condominiums.

We live in many styles. What we do <u>not</u> live in -- those of us who have choices -- are large, congregate settings.

There are only two times in our lives that those of us with choices live in large, congregate settings -- in our college years, a time when most of us left dormitory living as quickly as possible; and the other time we -- those of us with choices -- lived in large congregate settings was in the Army, and then only briefly, because even the Army knew that people who have other choices would not stay long in a system which used large, congregate housing.

Although all of us here live in many ways, in many styles of housing, <u>not</u> <u>one</u> <u>of</u> <u>us</u> <u>here</u> beyond brief college and Army days <u>ever</u> chooses to live in large, congregate housing.

Why don't we ever choose large, congregate housing? Remembering my dormitory, I found it dehumanizing to have so few choices; I was bothered by the lack of privacy; I felt an isolation from the neighbors around the building.

It becomes a moral issue -- a matter of simple human and civil rights.

We, who are the able majority, cannot choose a style of living for the vulnerable minority of mentally retarded people that none of us ever chooses for him or her self. I cannot say that a life style that's not good enough for me is good enough for my son.

As a matter of morality, of fairness, of human and civil rights, we cannot choose by our funding large, congregate living arrangements for the vulnerable among us.

S. 2053 would make a positive difference in the lives of mentally retarded people !!!

STATEMENT OF BOB JIRIK, SELF-ADVOCATE, ST. PAUL, MN

Mr. Jirik. Thank you, Senator Durenberger and Senator Chafee, for permitting me to speak today.

I am also handicapped. I was the guy that was always in a corner. My folks never gave up with me; they wanted me to be somebody some day.

They wanted to put me into an institution—the school system did. They said I was retarded because I couldn't read. I had what they call "word blindness." I don't know what it is, but anyway, I have been working at Univac for 17 years. I have had other jobs, and I have made my own living, and I deserted my dad about a year ago, and I am taking care of my mother and dad, and I'm still working at Univac.

To the best of my ability, I am doing what I think is right. I have gone to Washington; I have talked to the Senators there. I have talked to Mr. Durenberger once or twice about certain things about the handicapped.

But I think more facilities should be out where the handicaps can help themselves. They will get more out of it than if they would be in an institution. If they have to be institutionalized, let them be institutionalized. Let them decide, not somebody else.

Senator Durenberger. Bob, you are getting stronger as you are going along.

Mr. Jirik. Wait—I ain't through yet.

Senator Durenberger. Oh! [Laughter.]

Mr. Jirik. And there are a lot of things that I have talked to the Senators about for about 15 years. Everybody says, "Oh, maybe we'll do this", "Maybe we'll do that," and now I have my name in the Congressional Record. People have been noticing me now, and Univac has run a story about my life. And I am proud to work for Univac and people that thought something of me.

Thank you very much.

Senator CHAFEE. Thank you.

Senator DURENBERGER. Thank you, Bob. Daryl Pederson.

[Mr. Jirik's written testimony follows:]

In Support of Community & Family Living Amendments to S2053:

My name is Bob Jirik and I want to say that I agree with the Community and Family Living Amendments to Senator Chafee's Bill, S2053. I think that my story is proof that handicapped individuals can become productive members of society if they are given a chance and are not just shoved into the corners of institutions.

I have a learning disability called "word blindness", a form of dyslexia, that causes me to see words in reverse order. When I was young, there were no special education programs to help me read. Instead, when I was still school age, state personnel wanted to institutionalize me.

After I got out of school, I worked at a number of jobs such as setting pins at bowling alleys and caddying at golf courses. For a while, I was hired to carry books to legislators at the state capitol, but I lost that job when I couldn't pass the written test for clerks.

I wanted to learn to read so I could take care of myself, but my rehabilitation counselor told me to give up the idea. She told me I would never be able to read or write. But Carl Grittner, a school superintendent, arranged for a remedial reading course for me at the University of Minnesota. That's when they found out that I had word blindness.

Mr. Grittner later arranged for a course in remedial reading at Maxfield High School, using the "talking typewriter" method of visual education. The talking typewriter helped me to read somewhat, but not very fluently. About that time, I got a job at the Emporium Department Store in St. Paul. When the Emporium closed, I got a job as a janitor at Sperry Corporation. After a few years, I was promoted to stock attendant, even though my reading ability was somewhat limited. But my supervisor helped me and by sheer determination I was able to handle the job.

Meanwhile, I found a reading method that has helped me further. I go to school one night a week and a special tutor gives me a lesson using the Laubach method, used by the Martin Luther King Foundation.

I was pushed into a corner until well along in life. But in spite of all this, and because I refused to give up, I am now a taxpayer and not a burden on the state. I am presently serving on the Minnesota Governor's Planning Council on Developmental Disabilities and am on a special advisory committee for the mayor of St. Paul.

I am 63 years old and still want to learn so very much. It hasn't been easy. The trouble is that many people don't even have a chance to prove themselves. They are put into institutions and drugged to keep calm. Their minds become twisted and they feel hopeless. I think they need a chance. I also think that less severely handicapped people could be used as overseers in helping them make the transition from institutional to non-institutional life. Everybody deserves a chance. I think that this bill would help give it to them.

Robert J. Jirik

Robert J. Jirik

August 8, 1984

STATEMENT OF DARYL PEDERSON, SELF-ADVOCATE, MINNEAPOLIS, MN

Senator **DUREUBERGER**. Daryl, you asked to be a witness here today, and we're really glad that you decided to come.

Mr. **PEDERSON**. It was nice for you to invite me here, Senator Durenberger and Senator—Dolsee?

Senator **CHAFEE**. Chafee.

Mr. **PEDERSON**. Oh, Chafee. OK.

I think the people should have been in their community a long, long time ago, because the community is better for them.

OK, first I'm going to tell you that I was in an institution. They decided—I was in there about 10 years. I went in there when I was about 7 years old, and they just kind of thought that it was best for me to go into a community.

And like, you know, in the schools they've got all these things that not they had before and they've got them now that can teach you how to do things, to add numbers and that.

And I think, you should take a couple or 3 hours and go visit a group home, like a training apartment, and then you'll see how the people are doing. I have a job now and can do anything in the community. Like, I just think they improve a lot since they been out of the institution. Like, they can show you many things that they know how to do, and that.

Like, these things need to be more, and the economy need to bring more people in the community, 'cause they're not doing them no good in the institution, 'cause they got more good things from what they're doing now.

About 5 months, they can be out in their own apartment and managing their own self, and that

Senator **CHAFEE**. Do you live in your own apartment, Daryl?

Mr. **PEDERSON**. Yeah.

Senator **CHAFEE**. Do you take the bus to work?

Mr. **PEDERSON**. Yeah. I take the bus, and I do everything on my own now.

Senator **CHAFEE**. Do you cook for yourself?

Mr. **PEDERSON**. Yeah.

Senator **CHAFEE**. Does somebody come in and help out?

Mr. **PEDERSON**. No; I do all that stuff by myself.

Senator **CHAFEE**. You do your own shopping and everything?

Mr. **PEDERSON**. Yeah, I do that, too.

Senator **CHAFEE**. Fine. Thank you very much.

Senator **DURENBERGER**. Daryl, are you finished with the things you wanted to say?

Mr. **PEDERSON**. Yeah.

Senator **DURENBERGER**. Thank you, also, for coming.

[Mr. Pederson's written testimony follows:]

August 6, 1984

Roderick A. DeArment, Chief Counsel
Committee on Finance
Washington, DC 20510

Dear Mr. DeArment:

I would like to testify on August 13 in support of the "Community and Family Living Amendments". Following is my testimony.

"My name is Daryl Pederson. I lived at a state institution in Minnesota for about ten years, from 1960-1970. I went there when I was seven years old. Back then they didn't have group homes - times then were not very good. Parents then didn't have any other choice - they couldn't stay home all the time to take care of people and never have a vacation.

Now there are good programs in the community and good possibilities so that I think everyone should be able to live in the community. I think it's cheaper for the state, too.

I now live in my own apartment and have a full-time job. There are big changes when people move to the community - they get their own privacy, they have more confidence, they learn to do more by themselves. You can't learn those things in an institution - you have to be out in the community to really experience it and learn.

I think people and institutions should look at how much people can do and not judge which persons are better off in the institutions and not judge which people will <u>never</u> be able to move out and learn to do things. You would have to see people who have moved out and see how they have changed to really know.

I know this is controversial and a lot of politics are involved. It will take ten years to decide if they want to close institutions. They should send people to a group home for a week and see how they do and take a second look. They should do it now. Those people are ready and waiting to come out."

Sincerely,

Daryl Pederson

Daryl Pederson
2115 Blaisdell Avenue South
Minneapolis, MN 55404
(612) 874-8117
(or leave a message at (612) 874-6650)

cc: Senator Dave Durenberger
1020 Plymouth Building
12 South 6th Street
Minneapolis, MN 55402

353 Russell Senate Office Bldg.
Washington, DC 20510

Senator CHAFEE. Mr. Thomas, I am not sure exactly what you were saying. I understood the study that you were suggesting, and I gathered the point there was, "Let's see if this works." In other words, compare apples to apples. You take a group who let's say have a 40 IQ in an institution, you keep some in the institution and send some out in the group home, and see which ones do best. Was that your theory on the "apples and apples?"

Mr. THOMAS. Well, this is a research technique that is very prevalent in business today. When we develop something in business, we will use something that is always a control, something that is always a base that you compare off of. Therefore, if you were to examine, under this situation, you would have a population of retarded that had similar problems, and you run it as a basic control, keeping careful records.

Senator CHAFEE. Right.

Mr. THOMAS. You have two other units running left and right that would read that the same way.

Senator CHAFEE. Now, isn't that what the Penhurst study was all about?

Mr. THOMAS. Well, I think it might have been. But I wonder if they controlled the variants. I do not know enough about that detail. But if it is, then I would refer to it in the sense that it has an option.

Senator CHAFEE. It seems to me the problem we've got here is that a lot of people say some are best in institutions, some are best out in the community homes. And Mrs. Rosse has given the opposite testimony to yours.

Suppose we follow what you recommend—don't put everybody out, don't press everybody to be out in a group home. Then what happens? Why is it going to be any different than it is now?

What motivation is there? There is a large building bias—not just for the money. Let's say we have the funding equal for the group homes as it is for the institutions. But obviously there are people who have a deep commitment, for reasons which are understandable—whether it is their job, the employee's job, the ASME job—they are running an institution, and people just in human nature aren't going to disband an institution.

Mr. THOMAS. Well, 2053, in its very style, is forcing. It is saying: "These are the rules, and if you are not in these rules we will disqualify you for medicaid." Under that kind of a force, you are starting to see—and I happen to be on the advisory board of the Faribault State Hospital—amazing improvement in the developing of the other facility. What keeps coming back in this testimony is what the large institution is perceived to be. And I think what is happening here is, because of the force of 2053 and picking it up in the small success that you have had in your State, et cetera, you are destroying the ability to take a structure that is already in position, which given time and opportunity can perhaps beat the whole concept of 2053 without the cost of the physical facility, with the encouragement of the citizens who just want the chance to prove that.

We in Faribault do, and we think we are doing an excellent job. That force has been a healthy thing. This controversy has been a healthy thing. But the history of the State institution and the large institution perhaps is, sort of on a roll. In this great modern generation, where everybody has human rights, et cetera, et cetera, certain things are setting in that are starting to roll because of not really the facts.

Therefore, I urge that there is opportunity to take the fabric that is there and do a lot more with it rather than close it up.

Senator CHAFEE. All right.

Ms. Rosse, I thought the point you made, the last point you made, was a very, very significant one, and that is, by the fact that these residents are out in a community, that the community acquires an involvement with them.

Now, this isn't going to be true everywhere, but certainly it is where there is some sort of a fixed residence. It probably isn't going to come up where everybody is moving all the time or in an impersonal apartment complex, but where they recognize the residents in this small home you have—what was it called?

Ms. ROSSE. Single Creek Option.

Senator CHAFEE. Single Creek, where they came into the store or they went to the park, or the neighbors saw them and began to take a proprietary interest in their well-being, which is so much better. It's a side advantage that I think is terribly important; whereas, if they were off in some institution, way off someplace in the country, nobody would ever see them.

Ms. ROSSE. I think it's a tremendous advantage. And just to clarify, we are in the middle of an apartment complex in Brooklyn Park. That's kind of a blue-collar, transient almost, community. There is a lot of section 8 low-income housing around us.

I didn't expect it to happen there. I knew that it had happened in Minnesota's previous history, when we put a home in a very nice residential neighborhood, that people would come forward and help. But this happened also in an apartment area, just because we are back and forth and back and forth. I think the point that I made, the strength of the community continually watching over the care of people would happen anywhere, provided we've gotten small enough that we aren't isolated. If we can have a store on site, we're not going to go out to the neighborhood store. If we can have park grounds on site because we have lovely large acreage, we aren't going to go and use the community parks with everyone else. And that's the strength of smallness and the strength of the community. When you are small, you have to get out there.

Mr. THOMAS. Senator, you are not of the opinion that the large institution doesn't bring the people in there into the community. And wouldn't it be interesting to note how frequently those large institution people visit the community? And while this is certainly a very positive testimony, it may be true that in Mount Olivet those people visit the community more frequently.

Now, the assumption is that this is a restrictive-care unit. And what is restrictive care? But believe me there is a lot of visitation outside of a large unit.

Ms. ROSSE. We don't visit the community; we don't take trips into the community, we are a part of the community. My son goes to the same physician as I do.

Mr. THOMAS. So do a lot of the other people. So do a lot of the other people.

Senator CHAFEE. Well, let's not debate this now.

Mr. THOMAS. Many people work in the community that stay in the large institutions.

Senator CHAFEE. OK, fine.

Bob, I want to thank you very much for coming and giving that fine testimony. Univac is doing well, is it?

Mr. JIRIK. Yes; they are doing well. And I also take a bus to work.

Senator CHAFEE. Do you?

Mr. JIRIK. Yes, sir.

Senator CHAFEE. And Daryl, I appreciate your coming very much.

Mr. PEDERSON. Yeah. I would like to go to your State.

Senator CHAFEE. Well, I would like to have you come.

Mr. PEDERSON. Well, let me know when.

Senator DURENBERGER. He's leaving at 6, Daryl.

[Laughter.]

Senator DURENBERGER. Thank you all. The hearing is adjourned.

[Whereupon, the hearing was adjourned at 4:49 p.m.]

[By direction of the chairman the following communications were made a part of the hearing record:]

TESTIMONY ON SENATE BILL 2053

"COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983"

Presented Before the Senate Finance Subcommitte on Health

by

Leonard W. Levine, Commissioner
Minnesota Department of Human Services
Fourth Floor Centennial Office Building
St. Paul, Minnesota 55155
612/296-2701

Mr. Chairman, members of the committee, my name is Leonard W. Levine, and I am the Commissioner of the Minnesota Department of Human Services. I am before you to present testimony on Senate Bill 2053, the "Community and Family Living Amendments of 1983".

Senate Bill 2053 embodies many concepts that describe Minnesota's current program initiatives in services to persons with mental retardation and, as important, values that are shared by most Minnesotans. Chief among these are:

--support of family integrity by providing services close to family and friends;

--recognition that life in the community not only enriches the lives of all of us, it also provides a potent habilitative environment for persons with severe disabilities;

--recognition that careful service planning and assurance of quality in the service delivery system are essential;

--protection of the rights and benefits of current employees; and,

--that meaningful vocational training and employment opportunities are essential to the personal independence of persons with severe disabilities.

In these areas, Minnesota supports strongly the public policy and leadership demonstrated by S.B. 2053. Indeed, I can tell you from Minnesota's experience, that these are necessary elements of a responsive, humane system of public and private human services.

The concepts embodied in S.B. 2053 represent sound national policy and an affirmation of Minnesota's own policy initiatives. However, the mechanics of the current Bill present Minnesota with some severe, and possibly insurmountable implementation problems.

Senate Bill 2053 proposes a definition of "developmental disabilities" that is far more encompassing than current Minnesota laws. Currently, Minnesota statutes set forth clear criteria for determining the presence of mental retardation or mental illness. The Minnesota Legislature appropriates resources for the provision of services based on a clear, historical understanding of the nature of the services provided and the needs of Minnesotans who receive the services.

The "Community and Family Living Amendments of 1983" proposed definition is less well articulated than that which has been established by the Minnesota Legislature. By mandating the proposed definition, the Congress will create conflicts and confusion between Federal program leadership and Minnesota's established policy aims. However, and more significantly, it is unlikely that an adequate infusion of resources from federal or state sources will be available to provide quality services to newly eligible persons. The result will be fewer and eventually poorer quality services to meet the human and habilitation needs of the most vulnerable among us.

In addition to the admirable program policy goals of S.B. 2053, the Bill represents a major effort to align the federal government's funding policy with its human service program policy. We concur with this concept and assert that without such an effort program policy goals cannot be effectively implemented.

As federal program policy has shifted rapidly away from the provision of "care" in large, segregated facilities and toward/small, community-integrated, habilitation-oriented services, federal funding and regulatory policies have been slow to respond. The result has been a clear federal emphasis on community-based service delivery with funding and regulatory policy continuing to provide incentives for providing services in large "care" facilities. Minnesota's efforts to respond to this change in program policy in the face of federal funding and regulatory mechanisms that encouraged the development of large facilities and discouraged the development of small, community-based facilities has been labored and has resulted in costly and protracted litigation. In this regard, Minnesota's experience has been similar to that of some other states.

Recently, the advent of the medicaid home and community-based services waiver has been a first step towards aligning federal program and funding policies, and has stimulated a significant amount of activity related to the development of small, community-based services. The medicaid waiver is a first step which deserves continued support and study.

Minnesota has followed the federal policy lead by beginning implementation of the medicaid waiver. However, we are beginning the waivered services program initiative in an environment that is the product of following the direction of federal funding policies in the not too distant past. The existing service system is one in which only 636 Minnesotans with mental retardation live in community-based ICFs/MR of six or less; 2,198 live in community-based ICFs/MR of 7-16; 1,527 live in community-based ICFs/MR of 17-99; and 841 live in community-based ICFs/MR of 100 or more. In fact, we responded to past federal funding incentives so well that Minnesota now has the highest per capita rate of placement in ICFs/MR with more than 16 residents of any state in the nation---110 per 100,000 population. By comparison Louisiana is a close second, and West Virginia has the lowest rate---9 per 100,000 population. I think that it is safe to draw at least three conclusions from these data:

--measures to implement S.B. 2053 must be vastly different from state to state to allow for the considerable differences that exist among the states;

--Minnesota and some other states will be faced with a monumental administrative task; and,

--the proposed sanctions for not complying with the provisions of S.B. 2053 would be uniquely severe for Minnesota and the more than 4,500 individuals who will be affected.

Minnesota is committed to changing our service configuration to achieve a greater variety of small community-based service settings. However, I am certain that the proposed planning and enforcement mechanisms, and the associated sanctions of S.B. 2053 would be disruptive to our efforts beyond estimate. I urge this committee to consider the damage that the sanctions and enforcement mechanisms proposed in S.B. 2053 will have on the long-run evolution of service systems in states like Minnesota, and opt for alternatives that build on the successes and lessons of the medicaid home and community-based services initiative, and the use of stronger positive financial incentives for states to achieve the program policy goals of S.B. 2053. In addition, I urge you to consider alternatives which allow for management flexibility for states and tie federal financial incentives to individually determined state goals for program size reduction.

In summary, I would like to reiterate Minnesota's strong and demonstrated support for the program concepts embodied in the "Community and Family Living Amendments of 1983". We share the same vision of the future for persons with severe disabilities. In Minnesota, we have a long tradition of providing humane and effective services to persons with severe disabilities. It is our intention to continue that tradition even more aggressively into the future. However, I must close by stressing that the current implementation and enforcement mechanisms of S.B. 2053 will present monumental, and possibly insurmountable barriers to achieving the goals of S.B. 2053.

August 13, 83 **A**

Dear Mr. Roderick H. Clement,

I am writing in regards to the bill S 2053, entitled "Community and Family Living Amendment of 1983" [illegible] the purpose of the bill is the gradual elimination of the state institutions and limited Medicaid.

We have a child aged 32 in a state institution. Due to our health we were forced to put him in at age 16. He is profoundly retarded and requires medication daily. This child along with many others is not capable of living in a smaller community. We bring him home on holidays, visits. He considers the institution his home. Many people working there are trained in handling these children and are capable of handling their needs [illegible] years of experience in [illegible] among [illegible] to [illegible] a retarded child [illegible] we would be concerned about their placement with statistics as high as they are [illegible] we would [illegible] be faced with dealing with the problems [illegible] reconsider in your passing of this bill as we feel these residents are entitled to an education and medication and hospitalization as any other resident of Wisconsin.

We sincerely appreciate your consideration of Bill S 2053.

Sincerely,
Mr. & Mrs. Edward Adams
509 E Oak
Boscobel, Wis 53805

A

3875 N. Humboldt, Apt. 8
Milwaukee, Wisc. 53212
Aug. 16, 1984

Mr. Roderick De Arment,

I am writing to state my reasons against bill S. 2053, "Community and Family Living Arrangements". This bill, in cutting funds to state institutions, would greatly affect my severely retarded brother, George Adamczyk. He is a resident at the Southern Wisconsin Center for the Developmentally Disabled, (SWC).

First of all, we love George and visit him often. We tried to keep him at home with us, but his unpredictable and violent behavior caused problems for our family of 6. We tried several places for George to stay; none worked out like the 'SWC'. There, George gets constant care from nurses, therapists, doctors and pharmacists. They can help him *immediately* if and when a problem arises. There are also recreational and educational opportunities, too.

We do *not* want George to live in a community-type setting, for he may hurt someone else or himself. This would be inappropriate. Please consider our case.

Thank you,
Ray Adamczyk

2730 S. Delaware Avenue
Milwaukee, Wisconsin 53207
August 22, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

Dear Mr. DeArment:

Enclosed please find our letter in opposition to Bill S-2053 which we would like to be considered as Written Testimony for the hearing on S. 2053 which was held in Minneapolis on August 13th, 1984 by Senator Durenberger.

Thank you.

Sincerely yours,

Susan Adler

Joel and Susan Adler

2730 S. Delaware Avenue
Milwaukee, Wisconsin 53207
August 22, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

Dear Mr. DeArment:

I am writing to you to express my STRONG OPPOSITION to Bill S-2053, "Community and Family Living Amendments Act" and to explain briefly why.

I and my wife are the parents and court appointed legal guardians for our autistic, retarded twenty-three year old daughter Lynn. We have lived in Milwaukee for over twenty-two years. We have gone through many terrible years due to our daughter Lynn being periodically transferred from program to program and institution to group house and group house to institution; causing our daughter to regress in her behavior and learning, plus a great amount of trauma each time. These moves were caused by funds running out or her reaching a certain chronological age (although not mental) or her violent behavior (group homes were not properly staffed to handle violent behavior). Finally, thank God, we were able through the courts to force her placement at the State of Wisconsin Southern Wisconsin Center for the Developmentally Disabled in Union Grove, Wisconsin, where she is now getting excellent care and treatment. Due to her periodic violent behavior, which, on occasion, causes severe self-inflicted injuries, and the fact that she is prone to respiratory infections, she has to be where she can receive immediate medical attention.

Her long term prognosis indicates she will need to remain in an institution permanently due to these problems and her retarded mental level of ten to twelve years old. Therefore, when we received word of the above-mentioned Bill being introduced to the U.S. Senate, we are in a panic. Our daughter's health, indeed her very life, is threatened by a traumatic forced move to a small community group home with limited if any medical facilities and a staff unsuited for violent behavior.

We understand that the National Association for Retarded Citizens-U.S. voted 60% for, 40% against backing this proposal. I'm sure the 60% who backed the proposal had family that could and perhaps should move out of an institution, but the 40% against have severely retarded family members with special handicaps that require more than some small community home could provide. I'm sure some State institutions are in a sad state, but this shouldn't force good institutions to close or force everybody out regardless of their conditions.

In this type of program majority rule shouldn't apply. We are talking life and death issues, not an election. This would mean to provide more appropriate facilities for 60% we are going to take away more appropriate, even life-saving facilities, from the other 40%.

Please do not let this Bill pass, on behalf of my daughter and all the other children like her in this country.

Sincerely yours,

Joel and Susan Adler

Milwaukee, Wis. August 9, 1984 **A**

Mr. Roderick De Arment;

I am writing this letter in opposition to Bill S-2053: Community and Family Living Amendments of 1983.

I have a son, John, 36 years old at Southern Colony, Union Grove, Wis. He has been there 30 years. He is blind, profoundly retarded, has to be assisted in toilet and in eating.

I am very well satisfied with the treatment and care he is receiving at Southern Colony. They have a staff of trained, dedicated people, a doctor nurse, and other help is always on duty. When John got sick, there was a hospital on the grounds where he got immediate attention, I know John is happy and well taken care of where he is.

John is unable to express himself and I doubt if he knows or cares about his civil rights. As his father I am pleading that he have a choice and I make it in his behalf that he stay where he is.

Respectfully submitted
Alexander Aiches
3523 W. Galena St
Milwaukee, Wis, 53208

1-414-344-1557

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24 August 1984

Mr. Robert DeArment
United States Senate
Room SD 219
Washington, DC 20510

In Re: S.2053 Commuity & Family Living Amendments of 1983

Dear Mr. DeArment:

The following are,I believe, sound reasons for opposition to Bill S.2053.

1 - The phasing out of Institutions for Retarded children is like phasing out progress in coping with and understanding the causes and effects of human problems and behavior.

2 - Medical pursuits would be curtailed and hampered by the placement of children in small group homes. Psychiatrics and psychologists could no longer present evaluation efficiently.

3 - The screening and training of personnel for small group care would be costly and, in my view, practically an insurmountable task. Oviously parents would have every right to be disturbed as to qualifications and adequate supervision.

4 - Emergency and immediate medical attention, How would this; or perhpas, how could this be be accomplished? By those in charge of a small group home?

It is my every hope that propoments of this bill do not us this cliche, "The reductions of govermental expenditures". Christianity is basic to our way of life. It spells Love, Understanding, Compassion and Sacrifice. We would live in Dachau fear if our conduct purported to be otherwise.

Sincerely,

Don Alferi

■ EQUIPMENT AND SUPPLIES FOR THE MEAT INDUSTRY ■ SPECIALIST IN EQUIPMENT, MOTOR, AND ELECTRIC TOOL REPAIR ■

American
Psychiatric
Association

1400 K Street, N.W
Washington, D.C. 20005
Telephone: (202) 682-6000

September 6, 1984

The Honorable David Durenberger
Chairman
Subcommittee on Health
Senate Finance Committee
219 Dirksen Senate Office Building
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

The Minnesota Psychiatric Society, a district branch of the APA (representing over 29,000 psychiatrists nationwide) is pleased to provide our comments on the Community & Family Living Amendments of 1983, S. 2053, the subject of a recent Minnesota field hearing by your Subcommittee. We request that these comments be made part of the Subcommittee's August 13, 1984 hearing record on this legislation which would phase out Medicaid funding for residential facilities serving more than six to nine disabled persons while entitling such individuals to receive a wide array of home and community-based services.

Both the Minnesota Psychiatric Association and our parent APA have been deeply concerned and committed to making the health care needs of the mentally ill, mentally retarded and emotionally disturbed -- particularly the most chronically mentally ill and retarded. We fully support the intent of the Community and Family Living Amendments: "the full participation of severely disabled individuals in community and family life" and have long articulated the need to provide appropriate levels of insurance coverage to enable these individuals to be treated for their medical illnesses enabling them to rejoin the producing, contributing national workforce. Improving the lives of disabled Americans -- whether physical or mentally impaired -- without question should be the goal of Congress, as it is the medical profession's; in particular. However, the intent and end result of the proposed legislation would differ markedly, were the legislation to be enacted as written.

This legislation would phase out entirely Medicaid funding over the next ten to fifteen years for mental retardation facilities that house more than three times the number of individuals in an average family household. States would be required to file written plans and timetables for reducing their institutional population to zero. During this phase-out period, severely disabled individuals would still be entitled to Medicaid coverage for institutional services only when no community or family arrangements are available, and provided that the total time such an individual has resided in an institution does not exceed two years. States would have the options to continue to operate institutional programs, but would have to do so entirely with state funds. Following the phase-out period no developmentally disabled person, irrespective of severity of impairment or the wishes of his or her parents or guardians, would be eligible for Medicaid coverage in an institutional setting.

The provisions of S. 2053 are based on arbitrary size limitations (facilities no larger than 3 times the size of an average household) & judgments regarding the needs of the mentally disabled (no parental involvement in decision-making), and supported by questionable cost analyses and interpretations of major studies relating to deinstitutionalization.

For these reasons, articulated in greater detail below, we must oppose enactment of S. 2053 as written. Many questions remain unanswered; many details remain confused. The experience of current Medicaid community and home-based care waivers might more appropriately serve as a guide to future legislation, particularly given the serious and tragic problem which befell countless of the chronically mentally ill when they were deinstitutionalized en masse beginning in the mid-1950's.

In 1955, there were 600,000 patients in the nation's mental hospitals. At about that time, the move to deinstitutionalize patients began. It stemmed partly from civil rights issues and a growing emphasis on personal freedom. It was also believed that community programs for the mentally ill were more humane and effective, not to mention cheaper than the so-called warehouses for the mentally ill, often with populations nearing 500 in some facilities. Unfortunately, those community programs were inexpensive indeed, they were nonexistent. Thousands of the chronically mentally ill flooded communities when state after state sought to close the institutions without the corollary commitment of funds to support adequate community services. Many of these people, unable to live independently, were forced into substandard boarding homes or shelters for the homeless. The Congress learned a number of years ago about SROs (single room occupancy) and the plight of the thousands of mentally ill living in the half-world of such facilities. More recently, the nation has similarly turned to look at the homeless. A recent Little Hoover report from the state of California has disclosed the vary same pattern of disregard for the disabled and elderly which had been leveled against larger institutions to be present in the now-burgeoning board and care facility industry in that state which has yet another repository for the deinstitutionalized mentally disabled and elderly.

Caring psychiatrists, other physicians and health and mental health personnel coupled with a small, but growing number of the patient and parent support organizations are still seeking means of combatting the stigma of mental illness which reduces the community concern or activity. They are still scrapping for dollars to support this community network which was to have been in place when the movement began. They are seeking, at the same time, to maintain a full spectrum of care settings, whether larger or smaller, whether "institutional" or "community based" (a misnomer about which we will speak later), which can best meet the particular needs of each of the chronically mentally ill of our nation.

The message which emerges from this painful history lesson of good intentions is that deinstitutionalization is good in theory, good for some in practice, but absent proper planning, data bases, personnel bases, community support and, indeed, money, it is fatally flawed. We are concerned that as written, S. 2053 contains many of the same pitfalls and holds out the same altruistic hopes as did the deinstitutionalization movement for the mentally ill.

WHO WOULD S. 2053 TARGET FOR "COMMUNITY" SERVICES?

Medicaid now provides for the health care needs of at least the financially indigent of all participating states. Many states have broadened that population to include the medically needy. Among those persons are mentally disabled individuals meeting the Medicaid state-Federal criteria. That program supports medical treatment, whether institution based or community based for the eligible population. (Mentally ill individuals, though financially eligible, are excluded from Medicaid coverage for hospital based care if they are between the ages of 22-65.)

Today, the Federal share of Medicaid funding is being reduced. States are being hard-pressed to provide sufficient resources to meet the current agreed-to coverage for those now eligible for the program. The legislation before the Committee proposes to broaden at least one segment of the population -- the mentally retarded -- who will by Federal Statute -- not state decision-making -- be eligible to receive Medicaid funding for health and other services (some of which have not traditionally been Medicaid funded). But utilizing the definition from the Developmental Disability Act to form the basis for the population to be covered, the legislation would expand Medicaid coverage to essentially all mentally impaired persons who may or may not now be living in the community the onset of whose illness occurred by age 22. The legislation proposes to broaden the population further, by encompassing individuals for whom onset of the disability occurred prior to age 50. As noted, it becomes irrelevant whether that person is residing at home or in an institution at this time. Thus, persons eligible for the services, by Federal statute, would include not only those now institutionalized with an illness onset at age 50 or lower, but those now residing successfully in the community who otherwise might not be Medicaid eligible. The legislation is creating a new mandatory category of "medically eligible" individuals (now included under Medicaid at state option) who must receive community-based care. Further, the measure allows states to include disabled persons now residing at home as eligible when the family has spent five percent of its adjusted gross income in their care. Ironically, the parents of such persons, and all others to be served by the program are given no opportunity to participate in either placement or case management decision-making. Last, the measure would extend, by option, to mentally ill persons, whether they reside in the community or in institutions at the very time Medicaid has never provided hospital-based care to the same population between the ages of 22-65.

Medicaid will be paying substantially more to provide a myriad of services -- some now not eligible for Medicaid eligibles. Funding availability aside, there is a serious question as to whether the service network necessary to support such a population actually exists or could exist in a community. It would support housing, rehabilitation, vocational activities, health care, and daily living care for a population as varied in level of care requirements as can be imagined.

FACILITIES VERSUS COMMUNITY

S. 2053 makes the argument that "community" is better than "facility." It would limit Medicaid payments to eligible individuals residing in a "community of family living facility" with a capacity no greater than three times "the number of persons in the average family household in the area in which the facility is located..." As the average family household in the U.S. generally runs between two and three, the maximum size of a community or family living facility would be six or nine individuals. The current literature offers no convincing evidence to support the premise that independent living skills can be taught only in certain-sized facilities or that given the same individual care -- which can be and is the case in any number of what the bill would consider to be "institutions" -- developmentally disabled persons progress better in small than in larger settings. (See for example Baroff, "On 'Size and the Quality of Residential Care: A Second Look," 18 Mental. Retard. 113 (1980) or Brown & Buard, "The Treatment Environment for Retarded Persons in Nursing Homes," 17 Mental. Retard. 77, 79-80 (1979).)

Community placement is ideal for many developmentally disabled persons but not all.

If our experience has taught us anything, it is that the starting point for any system of services for individuals with developmental disabilities must be the individual disabled person. Implicit must be the recognition that, like medications, programs, services, and settings cannot be prescribed uniformly on a class basis, but must be determined according to the specific needs and condition of each disabled beneficiary. Individualization recognizes not only that the needs of each person differ, but also that each client's requirements for services many change many times during the course of a lifetime. S. 2053, however, would subordinate the concept of individualized care to the programmatic requirements of a very narrow and absolutist treatment ideology. If enacted, S. 2053 would seriously disrupt the continuum of services necessary for individualized care, and in the process jeopardize the security and well-being of tens of thousands of this nation's most vulnerable citizens.

Of the approximately 128,000 persons residing in public residential facilities for the mentally retarded and developmentally disabled there has been testimony to the Congress that: 80% have I.Q.'s below 35 and a maximum mental age of less than 4 years; Sixty percent have one additional major handicap; 37% have two or more handicaps in addition to mental retardation; Fifty-five percent are unable to dress themselves; Fifty percent are unable to speak; Forty-nine percent are not toilet trained; Thirty-five percent cannot eat without assistance; and Twenty-five percent exhibit severe behavioral disorders that create danger for themselves and others.

While upwards of 96% of this nation's citizens with developmental disabilities already live either at home or in other community placements, those who remain in public residential facilities require specialized medical and other services merely to survive. They require intensive individualized care and programming from a variety of specialties and disciplines if only, in many cases, to prevent a deterioration in their current levels of functioning. State developmental centers are more than bricks and mortar. Advances in medicine and the behavioral sciences, judicial intervention, and Medicaid's ICF-MR program have transformed state institutions from predominantly custodial facilities to multi-disciplinary, patient-focused developmental centers which - at their best with adequate funding - reflect and extend state-of-the-art programs and services in the care and treatment of profoundly retarded, multi-handicapped individuals.

I have recently spoken to a number of people in our home state of Minnesota specifically about the medical needs of the severely mentally impaired. Dr. Frank Kiesler, who is the Medical Director of the Northland Mental Health Center, a Clinical Professor at the University of Minnesota, and a Past President of the Minnesota Psychiatric Society has suggested that there are many mentally retarded people whose care can best be provided in care settings which are highly organized and specialized institutions. Because of the nature of severe physical handicaps and/or because of more severe behavior problems, it is unsuitable for certain of the severe mentally retarded population to be cared for in the community. In Dr. Kiesler's opinion, their needs cannot be met in community group homes because of the demands placed on the staff. Only one of these patients/clients can monopolize staff time to the point of depriving other residents of essential staff attention. In the larger institutional programs such individuals have much better opportunity to realize maximum potential for them because treatment can be well organized for their multileveled and multifaceted treatment needs. In some group homes, staff may be reduced to simply coping with the disruptive behavior the severely retarded may present.

For many years Dr. Kiesler has provided psychiatric services for a large number of residents of two group homes for adult mentally retarded persons. One serves a more seriously impaired group who seem to always require group home organized residential services, and the other serves those who can be prepared for various degrees of independent living. Even in the latter case, however, many never achieve enough independence to permit fully "independent" residence outside of a group home. The most prominent among medical conditions complicating mental retardation are the following:

1. Severe behavior problems necessitating a large degree of environmental control and response.

2. Overt mental illness, such as psychotic symptomatology, in addition to the mental retardation. Oftentimes schizophrenia and manic depressive disorder.

3. Seizure disorders and management of epilepsy.

4. Self-injury resulting from hitting, biting, etc. and destruction of property.

5. A higher incidence of general medical conditions, such as gastrointestinal and neurological conditions.

When disturbed behavior patterns are manifestations of mental illness (usually either disorganized or paranoid schizophrenic disorders or depressed or manic affective disorders - which may be atypical in the forms they take), it is usually possible to treat the mental disorders and substantially improve the ability of the mentally retarded person to be managed in the group hoem and in the community. As is often true of non-retarded mentally disordered individuals, the mental illnesses tend to be chronic and require continuing treatment in order to reduce impairment and maintain stability. All of the persons living in the Northland Mental Health Center group homes are ambulatory, able to walk, ride in vehicles and regularly attend either day activities or achievement programs or sheltered workshops. For these individuals, general medical care is provided under the supervision of local specialists in internal medicine. He and Dr. Kiesler collaborate consistently.

In summary, the Northland Mental Health Center has tried to develop a rather flexible and sophisticated model for psychiatric services to the mentally retarded. In addition to stressing the importance of residential treatment, there are a significant number of our people whose care can best be provided in a more highly organized specialized institutional setting, such as the setting provided in our State Hospitals, for example, Faribault State Hospital and Cambridge State Hospital. Any attempt to change funding patterns to the State Hospitals without recognizing the importance of these specialized services, would be undesirable from a political standpoint.

The position and views we articulate are in no sense an apology for inhumane institutions. In our view, if the right to habilitation is recognized, camparable high quality humane care and habilitation must and can be provided regardless of whether or not it is in a setting deemed an "institution." We believe that state and other facilities of a size larger than envisioned by this legislation should remain available as an option for appropriate patients. S. 2053 forecloses this option.

As Throne has observed "The distinction between institutions and communities is a false one. A human community is composed of people and their institutions... Small and medium sized community-based residential facilities, group homes, and foster care homes are institutions too... The issue is not one of institutionalization versus deinstitutionalization... The issue is what kind of institutions best serve." (Thorne, "Deinstitutionalization: Too Wide a Swath," 17 Mental. Retard. 171 (1979)) S. 2053 prohibits a response to that issue by closing some facilities which might "best serve" some of the developmentally disabled.

COST

It is argued that this legislation will save Medicaid funds now expended for institutional care. It is argued that this legislation will save many of the developmentally disabled from lives lacking in habilitation, lacking in treatment. Both are patently false for a number of reasons:

(1) Medicaid requires "active treatment" to occur in all facilities now providing care for the disabled. That active treatment could be equally flouted by larger institutions or smaller facilities which spring up as the result of the board and care industry this legislation will set in place.

(2) As has been noted, the population base is appreciably larger than current Medicaid beneficiaries who are developmentally disabled. Even if "community care" costs less per capita, it will ultimately cost far more than current Medicaid pays for those now under the program.

(3) Economies of scale do not exist, particularly in meeting the needs of the disabled for physical therapy, and other forms of therapy routinely provided in so-called institutions.

(4) Saved Federal Medicaid dollars will be more than offset by State dollars utilized to provide care to those profoundly disabled who are not candidates for community-based treatment and to provide care for those persons whose needs require institutional care when "necessary" care fails.

(5) Substantially greater Federal dollars will need to be expended to expand appreciably the programs under P.L. 94-142 (Education for the Handicapped Act) which would be required to meet the educational needs of those newly returned to the community -- many of whom would be among the most profoundly disabled of the population.

(6) Cost estimates about community-based care reflect the costs associated with those now being treated in the community, not those who remain in institutions. The latter are in greater need of a large constellation of medical, social and rehabilitation services than the former.

It appears to us that what this bill represents is an interesting way to seek adoption of a program which requires substantial Federal, state and local funding in a time of severe economic constraints by premising its adoption upon the phantom availability of Federal-State dollars (through the troubled Medicare program) to pay its way. Given economic realities, however, we are deeply and seriously concerned that what will be created is yet another example of the failure of deinstitutionalization as the result of absent resources. We cannot afford another example of what we still are trying to resolve for the mentally ill to happen to the mentally retarded.

The MPS as well as the APA believe that Congress should not proceed with this legislation until many of the questions about appropriate care setting, service availability, financial resources, and population to be served are answered clearly.

Will these individuals be provided the various kinds of services they need? Can the quality of care and the environment be monitored? With states reducing their inspection budgets, can the greater number of facilities be inspected? Can the individuals needed to provide care for the developmentally disabled in small scattered environments be screened and trained? Can many thousands of small facilities and services in them be managed and supervised? Can the individual with skilled nursing and rehabilitative needs be cared for? Can the care be provided at a reasonable cost? If per capita costs increase significantly, will we be able to maintain the number of persons served?

The ongoing experience under the Medicaid Community and Home-based care waivers may provide some greater evidence. We hope the Committee will work with us as we mutually seek answers to these questions as well as those posed by the failed past deinstitutionalization movement which has affected the mentally ill.

Respectfully Submitted,

Lee Beecher MD
Lee Beecher, M.D.
Acting President-Elect
Minnesota Psychiatric Society

LB/tf/mg

Racine Wis
Aug. 13, 1784

Mr. Roderick De Arment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

Subject Public Hearing on S 2053 in Mpls Aug. 13, 1984

I am retired and I have a 12 year old daughter at Milwaukee. Her mother got the guardianship because while [illegible] [illegible] they and were placed in Foster Homes. They are doing more for their church and community than I ever could.

Therefore I am very much against Bill S 2053 which is allowing the intended into a jungle and they will [illegible] to take [illegible] whatever [illegible] they are unable to do.

Yours Truly
[illegible]
[illegible]
Racine, Wis 53403

arc
Association for Retarded Citizens
iowa

August 30, 1984

Executive Director
Mary Etta Lane

Robert DeArment, Chief Counsel
Committee on Finance
Subcommittee on Health
SD-219
Dirksen Senate Office Building
Washington, D.C. 20510

Re: Community and Family Living Amendments - SF.2053

Due to the time restraints of the August 13th field hearings in Minneapolis, Minnesota we were unable to present the enclosed testimony on behalf of the Association for Retarded Citizens/Iowa. We would greatly appreciate your forwarding this material to members of the committee for consideration.

Thank you for your assistance in this matter.

Sincerely,

Mary Leonard

Mary Leonard, President

ML/lr
Enc.

1707 High, Des Moines, Iowa 50309
(515) 283-2358 • Toll Free (800) 362-2927
State Member Unit of ARC National

TESTIMONY -- SF.2053

I present this testimony on behalf of the 87,000 persons with retardation in Iowa, the state and 85 local chapters of the Association for Retarded Citizens and as a mother of twin daughters with Downs Syndrome. My position is one of strong, affirmative support for the Community and Family Living Amendments and its concept of small, integrated family and community living settings, assurance of case management, individualized services and independent reviews of the level and quality of service. These principles promote a system of appropriate housing and services for persons with mental retardation and other disabilities. It is for this reason that the Association for Retarded Citizens/Iowa Board of Directors voted unanimous support for the Community and Family Living Amendments and the service direction represented therein.

ARC/Iowa is aware of numerous shortcomings in the residential system of our state. Through our communications network, residential realities and concerns have been communicated by parents, families and consumers confronting these issues at the local level. Additionally, the ARC disseminated and collated data through a housing survey that was funded by the Governor's Planning Council for Developmental Disabilities in 1983. The survey generated valuable information relative to issues and needs existing in the area of housing/residential facilities and programming. The study found:

- Several hundred non-elderly disabled people are residing in ICF nursing homes, are not receiving "habilitation and training services", and need a lesser-restrictive environment.
- At least 200 people at our State's hospital schools under ICF/MR licensure have been determined ready for community placement, but no community programs are available.

- The major barrier to community residential and services development is lack of funding and the extremely high cost to develop ICF/MR-licensed facilities.

Tital XIX funding availability, as it exists today, has caused hundreds of Iowans to be placed in medically-oriented facilities void of meaningful programming and support to foster independent functioning. The rural nature of our State and the manner in which Title XIX funds are directed have attributed to large numbers of persons being placed in institutionally-oriented facilities in order to provide service and funding access. The Title XIX Waiver is a hopeful sign that services may finally be taken to people rather than taking people to services. Unfortunately, the Waiver that would impact a large number of eligible individuals has, to date, been denied to Iowa. Consequently, persons remain concentrated in facilities ranging from 30 to nearly 800 residents. The future for our most vulnerable population continues to be bleak, as funding streams do not presently encourage or permit essential support to maintain smaller programs. We are, therefore, pleased that many of these issues and shortcomings have been addressed within the SF.2053 legislation and the proposed ARC amendments.

As a parent who has been involved in the ARC movement for over 20 years, I have had the unique opportunity to witness the evolution of different types of services and the impact they have had on those served. In Iowa City we have struggled to develop a network of small, group homes and a strong system of in-home support to deter hundreds of children and adults from permanent institutionalization. I have watched individuals thrive through access to specialized programs and experience personal growth in settings which nurture individuality and independence. They have developed rapport and meaningful friendships among the staff who serves them, as well as neighbors and members of the community.

One of Iowa City's more prominent citizens, Bill Sackter, attained a degree of fame from a television story depicting his life entitled, "Bill".

Mr. Sackter, who died in 1983, spent the majority of his life in the back wards of an institution; and the impact of his existence there is indelibly imprinted upon our memories. For years, his individual personality, potential and dignity was locked away for the sake of institutional order and uniformity. In light of his remarkable achievements after his release, I cannot help but wonder what contributions Bill would have made to society and to our community if he had been afforded a home environment conducive to heightened self-worth and independent living.

How many individuals like Bill are currently living in similar situations? How many people who have never had the opportunity to be part of a neighborhood and benefit from their right of participation as a citizen in our society?

On behalf of the Association for Retarded Citizens I appreciate the opportunity to share these views with members of the committee and urge your positive consideration of SF.2053 with ARC/US recommended changes.

Submitted By:

Mary Leonard, President
Association for Retarded Citizens/Iowa

A

arc
Association for Retarded Citizens
Northwest Communities

August 28, 1984

Roderick DeArment, Chief Counsel
Committee on Finance
Washington, D.C. 20510

Dear Mr. DeArment,

We are writing in support of S.2053, The Community & Family Living Amendments of 1983.

Our ARC has advocated for services for persons with mental retardation for many years now. Most persons with developmental disabilities reside in the community, and yet we have been unable to develop a truly comprehensive system of community services. Part of this has been lack of funds available to meet the needs of everyone.

We consider S.2053 truly landmark legislation. We would be able to use Medicaid funds to expand services in the community which heretofore have been nonexistent. Shifting the federal share of Medicaid funds from institutions to community based, integrated programs would mean that, for the first time, many persons with developmental disabilities would have access to programs & services. Also, shifting medicaid funding from institutions to community living facilities, would provide a more normal way of life for persons with d.d.

We have long advocated for the rights of all persons to live in the least restrictive setting. Institutions can hardly be considered "least" restrictive. While passage of S.2053 would probably result in the closure of most of these facilities, there are provisions built into the bill which would protect the interests of the parents and residents currently residing in institutions. It also provides safeguards on the rights and interests of severely disabled individuals as they seek out alternative community support.

We strongly support and urge the passage of S.2053.

Sincerely,

Sylvia Kloc

Sylvia Kloc
Executive Director

cc ARC/M
ARC/USA Governmental Affairs Office

12259 BEECH DALY • REDFORD, MICHIGAN 48239 • (313) 937-2360

8

Aug. 22 – 84
Ruth Balstad
580 Madison St. apt 131
Burlington, Wi. 53105

Mr. De Azment –

I am writing to you in regards to bill. S. 2053 Community and Family living Amendments of 1983.
I have a child living in Southern Wisconsin Center in Union Grove, Wi. to have her moved, I feel would be very upsetting to her, she has had to many upsets in her life already She is totally happy in her surroundings now, Is well cared for in every respect. She has been evaluated by experts, and it has been agreeded this is the least restrictive envirroment in which she is able to function.
She is severly and profonally retarded.
I am against this bil and if she were to be placed in a group home she would not have the care, supervision, medical attention which she has now. And I would never have a moments of peace and a feeling of security for her, that I now have.

I am a widow
69 years of age
and handicapped

Sincerely
Ruth Balstad
580 Madison St. #131
Burlington, Wi. 52105

August 17, 1984

Senate Finance Committee
Subcommittee on Health
Washington, D.C. 20510

Sirs:

Subject: Proposed Bill S. 2053
"Community & Family Living Amendments of 1983"

This Bill would do severe physical and emotional damage to brother and sister who are residents for the developmentally disabled at the Southern Wisconsin Center in Union Grove, Wisconsin.

To have them live in a group home within a community would expose them to dangerous situations well beyond their very limited capabilities of understanding and physical well-being because society does not fully comprehend their special needs. Also, there are such people, in the outside world, with ill-meaning, perverted minds who need only to offer candy or a toy to them and have full intent to do harm that my unsuspecting brother or sister could end up molested and/or murdered! A community group home cannot provide the excellent care and the safety to their well-being as has been done at the Southern Wisconsin Center. I also believe that the relocating of the institutionalized people would be a very enormous, expensive procedure.

My brother and sister have been severely retarded since birth. They need 24-hour care and supervision for every basic human need, (feeding, dressing, personal hygiene, etc.) They could never relate to the society on the outside.

Because I do not want to see my brother and sister and all others in their group become abused, ill-treated people of the streets, I am strongly against the S. 2053 Bill.

This Bill would only set back the achievements of human rights for the retarded which families and other compassionate citizens have worked for so long and diligently.

Sincerely,

Maria Barribeau

Maria T. Bembenek-Barribeau
1907 East Howard Avenue
St. Francis, WI 53207

B

452 W. Francis Rd.
New Lenox, Il. 60451
August 13, 1984

Dear Mr. De Arment;

We are writing in reference to S 2053 - Community and Family Living Amendments of 1983.

Our son, Frank, is severely retarded mentally but physically strong and healthy. When we could no longer care for him we placed him in a church sponsored home. When this home's classification was changed so that residents had more personal freedom, Frank became very disturbed and in consequence suffered a fractured skull and the amputation of a finger. Eventually a court placed him in the Southern Wisconsin Center for his own safety.

Since he has been at the Southern Wisconsin Center he not only has been physically safe but has adjusted well to a more structured life. Also some problems relating to his care have been solved for the first time.

We feel that the care Frank is getting now is the best possible. We are 67 and 73 years old and would like to be assured that this care will continue.

The trend toward community small group homes is fine for many but would be tragic for others. We feel that state institutions are necessary for people like our son.

Cordially—
Ruth P. Beattie
Butler Beattie

B

Joliet,Illinois
August 23 1984

Mr.Roderick DeArment
United States Senate
Room SD 219
Washington,D.C. 20510

Dear Sir:

I am writing as the parent of a severely retarded son to express my opposition to the Senate Bill# S.2053-"Community & Family Living Amendments of 1983.

I feel that it would be very detrimental for his welfare to be placed into any other program as he has to have constant supervision to prevent injury to himself and others.

The fine institutional care he is receiving now has had marked improvement in his behavior and he is apparently happy with his environment.
This bill may be helpful to some of the less retarded persons but in the case of my son and others in a similar condition,it would be possibly even dangerous to their welfare.

I am asking that this letter will be considered as written testimony for the hearing that was held in Minneapolis,Aug.13 1984 on S.2053 by Senator Durenberger.

Yours Very Truly,

Emil R Belles

Emil R, Belles
412 Maude Ave.
Joliet,Illinois 60433

In re: Bill S. 2053 8-22-84 B

"Community & Family Amendment of 1983"

Dear Mr. Roderick DeArment:

I feel the well being of my mentally retarded, 32 yr old son, Michael Lee Berger (the mentality of a 2½ yr old) residing at SWC for over 15 years would be adversely Affected by the bill S. 2503.

The few times thru out the years my son was moved to what I thought would be a better environment, turned out to be a mistake.

Just one example, was a transfer to a place where they had beautiful surroundings, & a room of their own for each resident with a large picture window with a view. Nice you say? Sad to say the window only proved to be a place Michael accidently broke the glass receiving large gashes in his arm, & Having to be restrained by 5 or 6 rescue squad members to get him to the Hospital. Once at the hospital they managed to stop the bleeding but protested they could not keep him because he was uncontrollable, yelling & screaming like a 2 year old. Forgetting that after all that's what he was... a 23 yr old in his mind! To say nothing of the affect of this on my son. It took months back at SWC before he was his old self again!

So, I say I am strongly opposed to Bill S. 2053. Community placement? No! Maybe for some, but certainly not for all! Some retarded citizens & my own son could possibly be one of them are too unpredictable. Calm for days, months & maybe years & then the unexpected, the unpredictable happens. Too many unforseen Circumstances that could in my opinion eventually lead to a possible tragedy.

I believe that SWC & all other Wis Institutions are definitely the most acceptable & proven alternative to the proposed community placement.

Sincerely,

Mrs. Vivian Berger
904 Rosemere Circle
Manitowoc, Wis 54220

August 20, 1984

Roderick A. Dearment
Chief Counsel
Committee on Finance
219 Dirksen Bldg.
Washington, DC 20510

RE: Community and Family Living
Amendments of 1983 (S. 2053)

Dear Mr. Dearment:

The attached copy of a letter to the editor which appeared in the (St. Paul Dispatch March 27, 1984) was written by my wife, and reflects my position on SF 2053 as well as Minnesota's Title XIX Waiver.

I am in support of SF 2053 in principal. I understand the guiding principal of the bill to be that of rewarding the system the most, that best helps the mentally retarded citizen develop to his maximum.

I believe SF 2053 should make allowances for those larger institutions such as Rolling Acres, described in testimony by Gerald Walsh, (5 to a home in a large setting of 12 homes and supported by a congregation of 11,000.) Surely it would be a step backward to suggest this facility should not qualify.

Our son is currently in a group home of 165 men. I have confidence in the administration and staff of this home. I would like to think SF 2053 would encourage this group home to establish small group homes or SILS, etc., in close proximity to where residents work or receive day services and continue providing needed services.

I am in support of SF 2053, properly administered and monitored, because I believe the long range best interest of retarded citizens will be served by this legislation.

Sincerely,

Earl Bergerud

Earl S. Bergerud
2121 Como Av.
St. Paul, MN 55108

St. Paul Dispatch - March 27, 1984

[illegible] 1984

Letters to the editor

Suit services to each retarded person

We are parents of a retarded son who was once helped by Cambridge State Hospital and is now being helped by a community residence, Greenbrier Home in St. Paul.

My husband and I came home from an afternoon of listening to a Senate committee considering bills relating to the future of Title XIX regarding community versus state institution services for the retarded. After listening to testimony about which agencies would carry out planning assignments, which hospitals could [illegible] many contracts to AFSCME employees, and how to perpetuate populations in the state institutions so that communities would not lose jobs, we were distressed that not one senator nor professional in the field had spoken as advocate for the retarded people whom these institutions and jobs had been set up originally to serve. Somehow, in the fight to preserve jobs, income for communities and votes for legislators, there seemed to be little consideration given to the individual retarded person.

We feel strongly that services must be suited to each retarded person. If one individual is best served in his or her community, close to parents and family, that is where that individual should be. If one needs the sophisticated medical services available in the larger cities, that is where he or she should be. If one retarded person can best be served in the more rural setting of an out-state hospital, that's where that one should be. If one individual would benefit from vocational training programs, that person should be where those programs are available.

JUNE [illegible]

St. Paul

8

450 W. Francis Rd.
New Lenox, IL 60451
22 August 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

Dear Mr. DeArment,

I am writing you in regard to the proposed bill S. 2053, "Community and Family Living Amendments of 1983". I would like to express my concern that while the bill would benefit both the mildly retarded in many cases and the taxpayers, the more severely handicapped individuals would not be provided for.

My concern is a personal one as I have an autistic brother who is thirty-six now and resides in Southern Wisconsin Center. I believe that his needs are well met there and that removing him from this institution would create a hardship for my parents who are retired. My brother is strong physically and not easy to handle and my father has had a heart attack and is now suffering from back trouble disabling enough to require the use of a walker. This would leave his care to my mother who also must assist my father. She is a small woman physically and I am sure could not manage. This would mean hiring people to care for my brother and would also require special living arrangements for him.

When he was a child and lived at home we had no social life. I could not bring people to visit without wondering when my brother would decide to remove his clothing or smear feces over his living area which had to be locked as he was apt to run into the road. Little has changed for him and I do not think society would be too enthused about his habits. Caring for him is difficult and frustrating and I applaud those people who are willing to truly care for the"least of them". My brother is healthy and likely to outlive my parents. What then? What arrangements will be made for the many severely retarded who have no one to care for them?

I understand your concern for the improper institutionalization of many people but I hope you will take into account those cases for which it was truly a heartbreaking last resort.

Thank you.

Catherine B. Bitner

Catherine B. Bitner

[illegible] 21 - 1983 B

Dear Sir:

In regard to Bill S. 2053 Community and Family Living Amendments of 1983

This bill would have a severe effect on my Child if she were to be taken out of Central Center and put in a group home. She is being well taken care of there and [illegible] I am strongly against this bill as I know she would not function in a group home. I find Wisconsin institutions a very acceptable and humane alternative to the proposed community placements.

Sincerely

Mrs [illegible]

[illegible]

[illegible]

[illegible] 53040

B

Mr Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, D.C. 20510

Dear Sir,

We as parents, are very unhappy to learn that you want to close all centers for the retarded. We were relieved at the time we placed our son, to know there was such places for retarded people.

Our son David will be 30 years old Nov. 13 this year. He has been at the Southern center since the age of ten. He was hard to manage at the time and his behavior was bad. He has been very happy there with all of his life time friends. His behavior has changed greatly and he is much more calm and easier to manage. They are treated special and are accepted by all, also in public places of entertainment and resturants. People are amazed at how well they behave.

Southern Center is a place where these special people can have alot of freedom and hurt no one. I'm afraid the change would interfere with their behavior. People don't realize the special care they get at the Center.

In neighborhoods with group homes the neighbors would frown upon them and no doubt mistreat them. They would not trust them plus always give nasty glares.

Why deny them what little of life they can enjoy, being together. The Centers were built just for them.

Our son has come a long ways since he has been at Southern Center, and much easier to deal with.

I would like my letter to be considered as written testimony for the hearing of S. 2053, for Community and Family Living Amendments of 1983 held in Minneapolis on Aug 13th.

I feel our son would be withdrawn and hard to manage if a change was made.

It would be a good feeling to know our son would always have a home at Southern Center after we are gone.

The people at Southern Center with whatever knowledge they have, when ever we go down there, are always happy and carry on a conversation with us. They are smarter than alot of people give them credit for. You wouldn't know what it is like unless you had a retarded child.

I'm sure Mr Goretski, who is retired from the Center was a great credit for the running of Southern Center so smoothly. He was well liked by the children. He always kept the place so neat and attractive.

We hope you do right by them and make them happy and I'm sure you would have peace of mind.

Thank you.
Mrs Henry Bohl (Mother of David)
345 - 92nd St.
Franksville, Wis. 53126.

B

5835 Creekside Lane
Rockford, Illinois 61111
August 23, 1984

Senator David Durenberger, Chairman
Subcommittee on Health
375 Russell Senate Office Building
Washington, DC 20510

Dear Senator Durenberger:

We are asking that this letter be entered as written testimony to the hearing on S-2053 which you held in Minneapolis on August 13, 1984.

We have a son who is a resident at Central Wisconsin Center for the Developmentally Disabled, in Madison. He is severely handicapped, both mentally and physically, and requires constant care and immediate availability of medical and therapeutic assistance and facilities. He could not survive in a community living environment.

We are strongly opposed to S-2053 (in its present form) for the following reasons:

1. Mentally (and/or physically) handicapped is not a simple classification. The forty year old with fifteen year old capability certainly can contribute to and learn in a community environment. However, the severely handicapped, non-ambulatory, non-communicating individual of any age cannot learn or contribute.

2. There is no provision in S-2053 for those handicapped individuals who must have immediately accessible professional help available only in institutions large enough to justify the required staff of doctors, nurses, and therapists. Our son has frequent seizure activity which cannot be attended to by untrained personnel. This seizure activity cannot go unchecked without certain additional brain damage or death as a result. Either result is UNACCEPTABLE.

3. Few people know of the problems of the mentally and physically handicapped and the care required by such individuals. Anyone that has not visited an institution like Central Wisconsin Center is not qualified to formulate an opinion on the results of passing S-2053 and certainly not to promote or vote for its enactment.

4. The support of this bill appears to be primarily in the states that have not had good programs for the care and education of the handicapped. For those states, a state bill to accomplish the equivalent of S-2053 is the best solution. Some states have already done so.

5. Individual states are currently able to administer programs as they see best. This is in line with President Reagen's direction of returning powers to the states. S-2053 is in direct opposition to this.

6. The cost of caring for the severely handicapped cannot possibly be lower by placing them in community living environments. Cost of providing proper medical care would, by itself, be increased substantially.

7. The proposed bill will remove our freedom of choice, as parents, as to the facility which is best for our own child.

8. S-2053 is attempting to fix a problem that doesn't exist, or, if is does, <u>must</u> be fixed by the states in which it exists. The states which currently <u>have</u> poor programs for the retarded will not have better programs under this proposed legislation.

Thank you for accepting this as testimony to your hearing.

Sincerely,

Mr. & Mrs. John F. Boll

Mr. and Mrs. John F. Boll

Family Support Program
1206 Northport Drive
Madison, WI 53704
(606) 267-8819

August 23, 1984

Senate Finance Committee
c/o Mr. Rod DeArment
Chief Counsel
Dirksen Building - Room 219
Washington, D.C. 20510

Dear Members of the Senate Finance Committee:

I want to urge you to support Bill S 2053, the Community and Family Living Amendment of 1983, as proposed by Senator Chaffee. This Bill will promote the full participation of severely disabled people in community life by restructuring medicaid financing to purchase community based services. Presently, federal funds are being used five times more to support persons in institutional settings than in the community. This skewed funding pattern limits the options for severely disabled persons as well as their ability to have a productive and fulfilled life. Over the last two decades people with disabilities and their families have advocated strongly for the public to allow them to participate in society as much as possible. This philosophy has been supported by disability associations, federal, state and local governments. However, believing and conviction cannot change the system. Dollars have to support the initiative.

Today it costs over $30,000 to institutionalize a severely disabled person in one of the 3 State Disability Centers. With supportive services, every person who lives in one of the Centers could move to a smaller community residence or facility for the same or less cost as a State institution with a higher quality of life and a less restrictive environment. How can we morally and economically continue to earmark monies for institutions? We cannot. Now is the time to change. I urge you to support the Chaffee amendment to bring people with disabilities back to our community.

Thank you.

Sincerely,

Anne Booth

Anne Booth
Family Support Advisor
Dane County

AB;da

A service sponsored by the Dane County Unified Services Board

Rt#1, Box 71
Joy, Illinois 61260
August 22, 1984

Chief Counsel + Staff Director
Committee on Finance
United State Senate
Room SD 219
Washington D.C. 20510

Mr. Roderick DeArmett;

I regret that I have just recently learned of your hearings on bill S2053 and most certainly not in time to meet your August 3rd deadline to be accepted to appear.

However, I ask that my enclosed letter be considered as Written testimony for the hearing on S. 2053 which was held in Minneapolis August 13, 1984 by Senator Durenberger.

Please note here and note that I am STRONGY OPPOSED to

S. 2053 "Community + Family Living Amendments of 1983" which was presented by Senator John Chafee, Rhode Island November 7, 1983.

Thank you for your consideration of my letter. I pray that S 2053 will fail miserably.

Sincerely,

Nancy C. Bowker

Re: Bill S.2053: "Community and Family Living Amendments of 1983"

This bill would adversely affect my brother, Daniel Bruce Vaughn, a resident of Central Wisconsin Center, Madison, Wis. He has been in this wonderful institution where he recieves care that he needs to live.

My brother has cerebry palsy which quite extensive leaving him no movement or control of his entire body. Since Dec. of 1972 he has had a tracheotomy allowing him to breathe for the past 12 years. This condition makes him a total care patient who must be under constant doctor and nurse supervision. However my brother has a very wonderful and warm personality and his intelligence has never been questioned by those of his family who love him dearly and those who work with him.

We and also I pray, you as decent people and American cannot throw these "special" people who Do have feelings and know their surrounds into the chaos and uncertainty by closing all institutions across America and revoking ALL Medicaid funds.

At a time where there is to be NO discrimination against a person no matter their Race, Color or Creed; How in God's name can a law be passed discriminating against a person because of a birth defect or injury that has rendered them handicapped.

Please have no doubt in your mind that bill S.2053 cannot be passed to insure freedom for ALL!

I pray that as Americans and human beings of a decent and caring sort you will vote AGAINST the passage of this bill!

Sincerely
Nancy C Barker
Rt#1, Box 71, Joy, IL 61260

8

R F BRIDGES
5652 SCHROEDER RD
MADISON WI 53711

August 20, 1984

Mr. Roderick DeArment, Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, D.C. 20510

Dear Mr. DeArment:

Re: Bill S. 2053
Community & Family Living Amendments of 1983

We have received information on this proposal and believe there are many benefits for a high percentage of our handicapped. In the past, I have had the pleasure of working on the staff at the Madison Opportunity Center which is a local sheltered workshop for the handicapped and as a result, I realize the majority of the clients were functioning in the community and welcomed as neighbors, requiring a minimum of supervision or assistance.

It is also our privilege and responsibility to speak for Janet Bridges, our 27 year old handicapped daughter, as her legally appointed guardians, because she cannot speak for herself. Having severe cerebral palsy, she has required a great deal of care all of her life. Until about the age of 9, she lived at home. Her three sisters and both parents were needed to feed, bathe, and tend to her basic needs. The time came when her needs became more than we could handle. For the last 18 years, Janet has lived at Central Wisconsin Center and has had the care without which she cannot live.

A competent staff and many unpaid volunteers have furnished what we no longer could. Hand feeding all meals, which must be specially prepared, toilet routines, bathing, etc. She cannot sit up, stand up, walk or help herself in any way. For her, life anywhere will require the services of several loving, skilled and dedicated professionals. She, and many others that we are familiar with, could not survive in a group home situation without expensive, full time professional care and equipment. Just as a physician does not prescribe one drug for all diseases, or a judge impose one sentence for all violations of the law regardless of the crime, we cannot assume that what is best for some is best for all. There are many types and many degrees of handicaps. In our well meaning attempts to help some, let's not cause this silent minority to suffer even more by causing the closing of Central Wisconsin Center and many other excellent facilities.

Sincerely, Richard F. Bridges

Genevieve Bridges

Richard F. Bridges
Genevieve Bridges

August 15, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, D.C. 20510

Dear Mr. DeArment:

I am the mother of Christopher John Bunno. Chris was born with severe brain (micro-cephis) damage in 1968. Chris will be celebrating his 17th birthday on August 17th. His mental age is 2.8 months.

Chris lived at home with us for approximately 3½ years before he began to pose a nursing and medical problem, then we were fortunate enough to be able to place Christopher at Central Wisconsin Colony. This was 14 years ago this September. Upon each visit, I realize just what "total care" and "profound retardation" mean. He has received excellent care throughout the years. The programs that the Colony offers; programs for the blind (Chris is legally blind) the foster grandparent program (Chris's grandmother lived in Madison for years and never visited because she couldn't handle it.) Without such programs Chris would not have benefited.

The staff at the Colony has been most helpful and supportive thru the surgeries that he has needed.

I sit here writing to you, trying to imagine how different life would be today if a "Colony" had not existed for us and Christopher. The only answer I can come up with. DEVASTATING.

When decisions had to be made in reference to Chris's care; the social worker at the Colony was there to lend a sympathetic ear and good advise, often acting as a liasion between staff doctors and us.

I feel that the Central Wisconsin Colony serves a vital purpose in society. And to discontinue institutions for the retarded would be an added tax burden to the community that the child comes from. Where are "these small group homes' supposed to come from? You are saying that my son only needs total care for 2 years in an institution. YOU ARE WRONG!

Please consider this letter as written testimony for hearing S.2053 held in Minneapolis, August 13th.

Sincerely,

Mrs. Darla M. Bunno

Mrs. Darla Bunno

B

Mr. and Mrs. F. William Busselberg
1753 East Dartmouth
Mesa, Arizona 85203

13 August 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, D. C. 20510

Dear Mr. DeArment:

RE: S. 2053

PLease consider this letter my written testimony for the hearing on Bill S.2053 which was held in Minneapolis on August 13, 1984 by Senator Durenberger.

I am strongly opposed to the passage of this bill. I repeat: I am strongly opposed to any bill that will do away with the excellent facilities of an institution like the Southern Wisconsin Center.

It seems to me that the proponents of this bill have absolutely no experience with the severely retarded, such as my son who is receiving excellent care in the Southern Wisconsin Center. I am grateful that there is such a facility to care for our son--a facility that can give him the care we were not qualified to give him, but which he can receive in a facility like Southern Wisconsin Center by trained and qualified individuals. We endeavored to take care of him at home for eight years, but since he has never progressed beyond the one-year level and is completely dependent on others for help, we just were not able to take care of him any longer.

On two occasions, he was placed in a small group home. Unfortunately, it did not work out and he was returned to the Center. I can see no advantage to the proposal. It is an injustice to our children who are not able to take care of themselves. If this bill is designed to save the Government some money and give credit to those who are suggesting such a thing, I say it is an extreme injustice to these unfortunate children and to us as their parents.

Again, I am opposed to Bill S.2053!

Sincerely,

F. Wm. Busselberg

C

August 13, 1984

Dear Mr. De Arment,

I am writting to you about the bill S. 2053, Community & Family Living Amendments of 1983, and also want to tell you about our son, Randy, who lives at Southern Wisconson Center in Union Grove, Wisconson.

We want to tell you that we would not like to have the Center closed down and have Randy moved to a group home, as he has lived there for many years and he has come a long way with the care and treatment he gets there. The people who work there care for the patients and also love them as if they were their own family. I know this for a fact, as I used to go and see him every week at different times, when they did not know when I would come there, also my sister-in-law goes to see him quite often and she says he is always clean and well taken care of and is well content and happy there, in fact, the whole cottage and patients were well taken care of. Randy is responding to the persons who take care of him and he needs the care that he gets there as he has to have full time care at all times, as he has special medication during the day.

Randy is 30 years old, but is only mentally around 1/½ years.

We would appreciate it if you would consider Randy when you vote on this matter and think that it is best for him to stay at the Center, as it will hurt him if he has to be moved. These patients are better off in their surroundings, as when Randy first went to live there, it was very hard for him to adjust to the new place, now he is used to where he lives and is doing real well, but still can not be left unattended, as he is epileptic besides being retarded. Thank you for reading this and hope you consider our son and the place he is living in as it is the best home for Randy.

Thank you again,
Sincerely,
Mr. + Mrs. E. Carlson
1501 E. Bartam Rd. Lot 46
Tucson, Az. 85706

C

Dear Mr. Roderick De Arment,

This letter Pertains to State Bill S2053.

I think it would be a bad mistake to Close the places where the retarted live now.

I have a niece in Southren Colony, Union, Grove.

Julie is 21 yrs old having only the Mentally of an 18 month old Child. Julie can not feed herself, she is unable to talk. Julie just like's to set and play with a towel, she dosent Play with toys. Julie also has seizures which have to be controled by medicine. She needs care 24 hrs a day.

The Colonies they have know are very nice it would be a terrible Shame to close them. They also so have personal which are very cable of Caring for them. Thier are other ways to cut back rather then the retarted.

Thank you
Mrs Darrel Chapman

C

AUG. 28, 1984
ROBERT CORNETT
R.1, BOX 7
PRINCETON, WISC. 54968

MR. RODERICK DeARMENT
CHF. COUNSEL & STAFF DIR.
COMMITTEE ON FINANCE
U.S. SENATE

RE: BILL S.2053 - "COMMUNITY & FAMILY LIVING AMMENDMENTS OF 1983"

DEAR MR. DeARMENT,

THIS LETTER IS TO VOICE MY ~~[illegible]~~ OBJECTIONS TO BILL S.2053 WHICH WOULD REQUIRE THAT HANDICAP CHILDREN (OR ADULTS) SHOULD LIVE IN COMMUNITY HOMES.

MY DAUGHTER EILEEN, WHO IS HYDROSYPHALIC, IS 15 YEARS OLD. SHE LEAD A FAIRLY NORMAL LIFE FOR 10 YEARS UNTIL SHE HAD ANOTHER OPERATION FIVE YEARS AGO. SHE WENT INTO A COMA (~~[illegible]~~ VIGIL COMATOSE) DUE TO SEVERE BRAIN DAMAGE. SHE WILL NEVER WALK, TALK, EAT, OR HAVE ANYTHING BUT SPASTIC MOVEMENT AGAIN. SHE IS FED THRU A TUBE IN THE STOMACH. SHE NEEDS CONSTANT ATTENTION, BOTH FOR LIVING & MEDICAL.

SHE HAS NO LIFE SUPPORT SYSTEMS & COULD OUTLIVE ALL OF US BUT, WITHOUT PROPER MEDICAL CARE SHE WOULDN'T SURVIVE LONG. (SHE HAS HAD TWO SURGERYS IN THE LAST MONTH)

I STRONGLY OBJECT TO BILL S.2053 BECAUSE STATE RUN INSTITUTIONS ARE THE ONLY PLACE I HAVE FOUND THAT CAN ~~[illegible]~~ HANDLE HER PROBLEMS. MOST OF THE PEOPLE IN HER BUILDING, AT C.W.C. IN MADISON, ARE THE SAME AS SHE IS & COULD NOT SURVIVE AT HOME OR IN A COMMUNITY HOME.

THE ARE DEFINETLY NOT "SPECIAL OLYMPIC CHILDREN".

NOW, BEFORE YOU THINK SHE IS A "VEGETABLE", I WILL TELL YOU THAT SHE CRYES, COOS, & SEEMS TO RELAX WHEN WE VISIT. NOBODY KNOWS WHAT SHE IS THINKING OR HOW MUCH SHE CAN "THINK" BUT, I WOULDN'T CONDEMN HER FOR HER HANDICAP, WHICH I THINK THIS BILL WOULD DO.

I PAY $200 A MONTH TOWARDS HER CARE AND WITH FOUR OTHER CHILDREN TO SUPPORT, ON A LOWER MIDDLE CLASS INCOME, MY FINANCES ARE STRETCHED.

MY SECOND WIFE IS NOT HER MOTHER & WHILE SHE VISITS & CARES FOR HER MORE THAN HER REAL MOTHER, I CANNOT ASK HER TO ACCEPT ANY MORE BURDENS THAT WE ALREADY HAVE.

I WILL FINISH THIS LETTER BY SAYING AGAIN THAT I AM STRONGLY AGAINST THIS BILL (S.2053) & FEEL THAT YOU HAVE NOT VISITED OR INVESTIGATED THE SEVERLY HANDICAPPED.

THANK YOU,

Bob Cornett

COPIES TO.

SENATOR JOHN CHAFEE

MR. PAUL MARCHAND

SENATOR DAVID DURENBERGER

MRS. DEE EVERITT

SENATOR WILLIAM PROXMIRE

REP. TOM PETRI

D

Anthony A. DeAngelis Vice President|Advertising|Public Relations

Kemper GROUP

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Incorporated

August 13, 1984

Mr. Roderick DeArment
Chief Counsel/Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, D.C. 20510

Dear Mr. DeArment:

I would like to let you know that I am strongly opposed to Senate Bill S.2053 (Community & Family Living Amendments of 1983).

As the father of two retarded daughters, aged 17 and 13, I know first-hand what is involved in providing care for the mentally handicapped. That is why I'm concerned about the ramifications of S.2053.

If Medicaid funds to state institutions for the handicapped are cut or discontinued, we would probably be forced to close our facilities in Wisconsin. In the case of my children, the state institution provides the much-needed 24-hour daily care which I could not provide at home, and which could not be provided in a group home.

Under S.2053, the mentally handicapped would have to eventually be placed in a group home, but for only a maximum of two years. Then what? I would be forced to take my daughters back home. I would be back at square one, trying to find some one and some place to provide care. Because my daughters are both total care, they could not begin to function in a group home.

Senator Chafee claims widespread support for S.2053. In Wisconsin, we don't see any support. Our parents are against this legislation who have handicapped children, our state ARC is against it, and Senators William Proxmire and Robert Kasten have both publically announced they cannot support S.2053.

Those of us with severely retarded children are not being done any favors under the provisions of S.2053. In fact, this legislation will create more problems for us than it may solve. If Senator Chafee would like to provide a true public service, he should concentrate on going after those who have long abused Medicaid funds such as hospitals, nursing homes, doctors and others who have benefited greatly from federal monies.

My family and I need the Wisconsin institutions which have long provided outstanding care for the developmentally disabled. The cutback or elimination of Medicaid funds to our state facilities for the retarded and others under S.2053 would be a disaster. Those of us active in working with the handicapped plan to continue our work to defeat this ill-advised legislation which Senator Chafee has introduced. We invite you to join us in our efforts.

Respectfully,

Anthony A. De Angelis

Anthony A. De Angelis

Member New York Stock Exchange

D

August 28, 1984

Mr. Robert DeArment
Chief Counsel & Staff Director
United States Senate
Room S.D. 219
Washington D.C. 20510

Dear Mr. DeArment:

Regarding bill S.2053 titled Community and Family Living Amendments of 1983. I find it inconceivable that the purpose and outcome of this bill will benefit the good and welfare of our children, who now are in the State institution. At the present time these institutions are doing their utmost in the best care anyone could possibly give. First of all the child, no matter how severe their problem is will never get over the emotional trauma of being displaced from what theycall home. Then I can't see where this community living will give them the necessary medical attention they deserve. Where would you expect to find the necessary medical doctors, nurses and psychologists, and necessary personnel, etc. who are qualified with this kind of experience in community living without spending more money than it would ordinarily cost at the institution? Who would oversee and supervise on a constant watch to see, that the children would get adequate and proper care? Don't forget, now the responsibility will shift on government's shoulders, which you are part of. Are you ready to accept the potential failure of this enterprise? In my estimation you would be defeating your purpose. I certainly and vehemently object against this bill. Pordon my saying so, but I feel this bill has opened up a can of worms and it would end up in a catastrophy, to say the least. As a taxpayer I feel that my Grd child should have the best care possible such as the institutions are giving now since the child is happy, content and has a sense of security in their home (institution), please consider this--would you want anyone to take <u>your</u> child from your home? Think about it.

Sincerely yours,

Erco DeMarco

Erco DeMarco

August 20, 1984

Mr. Roderick DeArment
Chief Counsel + Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

RE: Bill S-2053 "Community and Family Living Amendments of 1983"

Dear Sir:

I am opposed to this bill because of the adverse effect it would have on our great institutions and the adequate care they give to our severely retarded.

The problems resulting from the changes being contemplated is highly irresponsible. There is no way retarded persons would receive the care they need without medical facilities. I think it is unreasonable to make community living mandatory.

I hope this will be considered written testimony for the hearing which was held in Minneapolis on August 13th, 1984 by Senator Durenberger.

Sincerely,
Florence De Meulenaere
800 E. Henry Clay
Whitefish Bay, Wi. 53217

D

8-10-84

De. Mr. [illegible]:

I am writing to you in regard to bill - 2035 - Community & Family Living amendments of 1983. My son is severely mentally retarded and in no way could he function in a place like community living. He need all the care and direction he receives at Southern Wis Center. He needs to be directed in very step he takes & under constant supervision. He would be very much at a loss in anything that would go on. This bill would would harmful to my son and people like him.

Thank You,

Mrs Mary DeSantis
1814-56th St.
Kenosha, Wis 53140

August 25, 1984 D

Mr. Roderick De Arment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC. 20510

Dear Mr. DeArment,

Re: Bill - S 2053
"Community and Family Living Amendments of 1983"

My husband and I are strongly opposed to the above bill. It is unrealistic to feel that all retarded persons must live in community group homes, and no person should reside in an institution no longer than 2 years.

We are the parents of a severely retarded boy, 24 years of age. Philip was born with cerebral palsy, and as a result is severely retarded. He has always been extremely hyperactive. His attention span is very short. We took care of Philip in our home for 13 years, and tryed everything that was possible to help him progress. We gave him much love and enrolled him in special schools and everything that was available at the time. We love Philip dearly and would never have even thought of having him live in an institution. However, at 13, he went through some very bad times. He regressed and his hyperactivity could not be controlled. There was nothing humanly possible for us to do to ~~make~~ control

- 2 -

him or make him happy. It was at the advice of the school principal at the "special school" he was attending, that we agreed to look into Wisconsin Center at Union Grove, Wisconsin. He was admitted into Tramburg Hall at the Center which had a behavior modification program. This was the hardest decision we ever had to make -- only parents of retarded children know how heart-breaking this can be! We found the staff at Wisconsin Center dedicated and extremely helpful. Philip was admitted with the plan that when and if he would improve, we would try to care for him at home once again. After a time, we took Phil home on a trial basis. He was re-admitted to the "special" school in Glendale. In a very short time, the bizarre behaviors returned, he became hysterical seemed extremely unhappy, refused to get dressed or go to school, and at school, he was regressing again -- would not even eat his lunch! It has been proven time and again, that our son functions better in a structured situation.

The Center took Philip back, and he has been there ever since. He comes home often on vacations and spends all holidays and special occasions at home with us. After a few days, he wants to go back to the Center. He keeps repeating, "Go back to school," over and over! He has adjusted well at Wisconsin Center, and we have been completely satisfied with the care and services he has been provided with. Our son does not adjust to change easily. We think community living is great for some persons, but every retarded person is different. We definitely feel institutions will always be necessary for certain individuals. We feel Wisconsin Institutions are very acceptable and a proven alternative to the proposed Community placement.

We honestly thought our boy would be back home with us, but we sincerely feel he is happy in his present setting. He is happy to come home, but only for short visits. He gets very anxious after a few days to get back to the Center.

We hope after reading this ~~your~~ letter you will understand why we feel Bill S 2053 should not be passed!

Sincerely,
Mr. & Mrs. Anthony Dentice

8/23/84

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

To Whom It May Concern:

We are writing in regard to Bill S.2053, the "Community and Family Living Amendments of 1983."

We are strongly opposed to having this Bill passed. Our son is totally helpless, and completely dependent upon others to feed, bathe, clothe, and care for him. The care he is receiving at Southern Center, a Wisconsin institution, is very suitable for him and very acceptable to us. Our son is severely handicapped, and has no understanding of family living, so a group home would not be beneficial to him.

I would like to repeat that we feel our son is an individual who needs the institutional setting, and that we are strongly opposed to the passage of Bill S.2053.

Sincerely,

Julius Drezek and Barbara Drezek
parents of Thomas A. Drezek

Julius Drezek
Barbara Drezek

E

33470 Mapleton Road
Oconomowoc, WI 53066
August 18, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

Dear Mr. DeArment:

I am the mother of a 24 year old profoundly retarded son who has resided at Southern Center in Union Grove, Wisconsin since he was 9.

I have learned recently of Bill S.2053, "Community and Family Living Amendment of 1983", and am very emphatically against this Bill.

It distresses me to even think of my son residing in a community setting. No "houseparent", no matter how dedicated, could guarantee that my son could not wander from the home and become confused and lost, possibly hit by a car, or be confronted with some other dangerous situation. The thought of him being tormented or taken advantage of by the type people we know exist in a community, makes me very upset. At Southern Center I have none of these fears, amd feel he has been safe, well cared for and happy.

I do not believe community living would be beneficial in any way to a severely retarded person. My son cannot talk and can make his needs known only to those who know him and his personality. He would not understand why strangers were not accepting him.

I have been very pleased with the care my son has received for the past 15 years at Southern Center. Please do not uproot him at this point from a place where he is content and happy.

Sincerely,

Bonnie Eckert

Bonnie (Mrs. Michael) Eckert

Re: Bill - S. 2053

E

Community & Family Living Amendments of 1983.

I am writing concerning my son David Matzat, 38 years old and a resident of Southern Colony since Feb 2, 1954.

He has known this center as his home now for 30 years, and I feel that he would get a lot worse if he was taken out of there. To not be near all the people there that have taken good care of him all this time would upset him greatly. Also to lose the friends he has there would upset him too.

When David was at home with us, I saw how he was treated by people his age, he came to me crying all the time because they called him all kinds of names etc.

To take him out of his home at Southern Colony would be a great injustice. I sincerely hope this does not happen.

Sincerely,

Mrs. Marvin Ellis
4414 So. Adams Av.
Milwaukee, Wi. 53207

F

August 27, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
~~United~~ States Senate
Room SD 219
Washington, DC 20510

Dear Mr. DeArment:

I am writing you this letter about a bill introduced by Senator Chafee. This bill which is known as bill S2053, the title which is "Community & Family Amendments of 1983".

We were unfortunate to have an R. H. condition which left our daughter retarded, very high strung and hard to control unless she is on medication. We tried to keep her at home but this was impossible because of the spells she would get.

In the last twenty years the institutions have improved to the point that I see no reason for closing them. These facilities which are being paid for are good and have good staff people. We can go there any time the place is open and we have never found any abuse to our daughter and she was always clean and well cared for.

In this bill Senator Chaffee wants these retarded and handicapped people to live in small community group homes, in which it would be impossible to give proper care and protection and also would be more costly.

After reading about and hearing of the many incidents athat are happening in these foster homes and child care centers, it is unbelivable that anyone could approve bill S2053. As was indicated in the news, they have only caught up with a few of these happenings and they stated it is only the beginning.

Therefore as a parent, I feel bill S2053 should be defeated.

Thanking you for your consideration,

Mr & Mrs. Lloyd Freiberg Sr.

Mr. & Mrs. Lloyd R. Freiberg Sr.
358 Lloyd St.
Fond du Lac, Wi. 54935

[redacted]

La Crosse, WI 54601
August 21, 1984

Mr. Roderick De Arment
Chief Counsel B Director
Committee on Finance
United States Senate
Room SD 219
Washington, D.C. 20510

Dear Mr. De Arment:

I am highly opposed to S-2053 known as "Community and Family Living Amendments of 1983. This bill would deprive parents, relatives or guardian, people in close contact with a developmentally disabled person from making any decisions. The decisions would be made by politicians supporting S-2053 who would have no idea what is in the best interest for the resident.

I have a 22 year old son with Downs Syndrome. He lived at home and attended special classes in the public school system until age 14. At this age he refused to continue school and had some behaviors that needed modification., He also lacked numerous self help skills and is nearly non verbal. He was placed at Northern Wisconsin Center for the Developmentally Disabled remaining there for 6 years returning home in November 1982.

He has learned to perform many of his deficient self help skills but even after 6 years still needs assistance in many areas: cleaning after toileting, brushing teeth, washing, garments with buttons, tying shoe laces and crossing streets account of traffic. These people can learn but it takes time, a long time, so the two year limit in a State Institution during the individuals' life time would be a complete waste of time and taxpayers money.

We are fortunate, La Crosse County provides some very good services for the Retarded and my Ron's training is continuing along with signing as a form of communication, but even La Crosse County cannot match the intensive type and quality services provided by our state institutions. There are many areas across these United States that provide few or no services for the Retarded. What would become of these people if they were forced out of state institutions?

S-2053 is also discriminatory. You could have two brothers; one with a severe sight problem and mild retardation, he would qualify for Medicaid Funds at a state school for the Blind and the other Brother who is severely retarded with a mild sight problem would not qualify for Medicaid Funds at a state institution for the retarded.

S-2053 is a bad bill and I do not believe it should become law.

Sincerely yours,

W. A. Frommelt

W. A. Frommelt
1826 Avon Street
La Crosse, WI 54603

August 29, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, D.C. 20510

RE: Bill S.2053
"Community & Family Living
Amendments of 1983"

Dear Mr. DeArment:

My daughter, Kim Foth, will be 17 years old on September 15. She is a resident of Central Wisconsin Center in Madison, Wisconsin. Kim has cerebral palsy and needs total care. Her physical abilities are limited to none. I brought her to Central Center for a 3-6 month rehabilitation program. However, after 1 year it was strongly suggested that she remain because of the lack of progress.

I am a single parent and it would be extremely difficult for me to care for her at home. It took a very long time for both Kim and I to adjust but the adjustment has been made and I feel any change now would be equally difficult, if not harder.

Central Center has been a God-sent gift to both of us. Kim is very well taken care of, involved in as many programs as possible and I visit or bring her home about once a month for the week-end.

I know for Kim and me closing the Center would be disastrous. Please reconsider. She needs the care and I need the peace of mind that she is getting it. Any change now could be devastating.

Thank you for reading and considering just a few of my feelings.

Sincerely yours,

Kathy Foth

Kathy Foth
Parent
1205 W. Cottonwood Lane
Apt. 13D
Mt. Prospect, IL 60056

G

August 10, 1984

To: Mr. Roderick DeArment
Chief Counsel & Staff Director-Committee on Finance
United States Senate
Room SD 219
Washington, D.C. 20510

Dear Sir:

Re: Public Hearing on S.2053 in Minneapolis Aug. 13, 1984
Community and Family Living Amendments of 1983

In response to and in addition to the testimony of others, we too are deeply concerned about the future of Central Center in Madison, Wisconsin.

Our daughter Kelly is currently a resident, very favorably so; of Central Center in Madison. It was our own personal decision to have her admitted there and she needs to be placed there for the duration of her life. There is no way she could be transferred to different living arrangements. She is blind and has Cerebral Palsy--she barely sits alone, does not walk, talk or communicate in any way. She is indeed in need of the 24-hour nursing care at the Center.

We as parents are quite upset upon hearing that these institutions are up for proposed closings.

In some information we have received; there is talk of only accepting these children for a period of two years. This may be possible for the less handicapped but not for a lot of children who are as handicapped as she. Our daughter has been there since she was 3 years old and she is now 14. She could not possibly remain at home with us as there is no way we could handle her at home or be able to afford 24-hour nursing care. Also there are no facilities in our community for such persons. We are very happy with the care she has received at the Center. She is always clean, wearing the clothes we send or take to her; and we are very happy also with the personnel who take care of her--they are always very accommodating to us regarding her.

We have heard of putting some of these residents in foster type settings--which upsets us tremendously. These may be fine for minimal handicaps but not for the severely retarded. If she were able to be in the lesser setting--she would be able to be home with us not a foster setting either. If we cannot care for her in our home--how could a foster home? Some of these children--as our daughter--<u>do need</u> the institutions.

We hope this letter has been somewhat informative as to our reasons for strongly opposing this bill.

cc's to:
Senator John Chafee
Mr. Paul Marchand
Senator David Durenberger
Mrs. Dee Everitt

Very concerned parents,
Mrs Tamara Ganley
Robert W. and Tamara Ganley

Please help us before it's too late!

G

January 5, 1984

Re: Bill S-2053
Title - Community and Family Living Amendments Act.

From: Mr. and Mrs. Ralph Gensty
2867 S. 14th St.
Milwaukee, WI 53215
(414) 672-2882

If this bill is passed, it will be disastrous to all present and future residents of institutions. It will cause emotional set-backs beyond anyone's expectations.

Our daughter Susan has been a resident of Southern Wisconsin Center, Union Grove, since fall of 1969. She is now 26 years old and has develped into a beautiful person. She would not be this person today if it were not for the superior guidance, medical attention and caring staff at S.W.C. working together in helping Susan develop all her possibilities

The before and after:

Physically: She wore waist high leg braces and almost constant use of a wheelchair.
Today : She is without braces of any kind, uses a walker vigorously and has a wheelchair standing by for distrant travel and Special Olympic races.

Mentally: She strived with one word sentences and became very frustrated.
Today: She can carry on short conversations, conducts word tasks with her peers, understands and knows the meaning of words such as Danger, Fire, Caution, Men, Women, Enter, Exit and more.

Sociably: She was content doing her own thing by herself
Today: She sings (and knows all the words), dances and joins in any activity offered and adds quite a bit of her own ideas.
Behavior: Tantrums, cussing and disruptive
Today: Now she is able to understand the importance of good behavior and the rewards of good feelings.
Spiritually: Joins in mass regularly and says she is God's child.
Emotionally: It goes without saying, today she is very happy and well adjusted. Susan's present program includes Special Olympics, trips, tours and sport events.

G

August 14, 1984

Mr. Roderick DeArment
Chief Counsel + Staff Director
Committee on Finance
United States Senate
Room S.D. 219
Washington, D.C., 20510

Re: S.-2053
Community + Family Living Arrangements of 1983

Mr. DeArment:

Our son Thomas has been a resident at Wisconsin's Southern Wisconsin Center for the Developmentally Disabled for 30 years, is mentally retarded, epileptic and with undifferentiated schizophrenia, and as such needs 24 hour attention and care. These needs have and are being provided for at the Center, something we have not seen provided for in like degree in any metropolitan community in our State - in spite of 20 years of deinstitutionalization and normalization efforts.

We are not against the philosophy expressed in S-2053, but are emphatically against the "position" statement that all institutions must be closed in 10-15 years. There is always going to be a certain number of our mentally retarded citizen population that can best be served in an institutional setting, which this bill will eliminate in its present form. That, we feel, is discrimination and denying of a necessary option and a personal right for residency and care.

Because some States operate "snake-pit" institutions is no reason to close down all institutions in the United States. By placing all retarded in community settings will not guarantee quality care for those presently needing institution care, any more then the past 20 years has presented an increase of "Street" and "Bag" People inhabiting the streets of our larger cities — the result of the "dumping" of institutional people to "less restrictive" facilities.

Please consider these situations before extending the present problems through institution closings. We can not afford to use this segment of our population as a potential savings (a statement that can be challenged) by moving them to the community.

We ask that this letter be considered as Written Testimony for the hearing records on S2053 which was held in Minneapolis, Minn. Monday August 13th 1984 by Senator David Durenberger.

Sincerely,
Lee George
Bernice A. George
5662 - N. Moraine Hills Dr.
West Bend, Wis. 53095
(414 - 334 - 3494)

CC: President Ronald Reagan
Senator Robert Kasten
Senator William Proxmire
Senator Robert Dole
Senator David Durenberger
Senator John Chafee
Senator John Danforth

August 20, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

This letter is being written to express our opposition to bill S.2053 "Community & Family Living amendments of 1983". Hopefully we can convince you there are other alternatives to arbitrarily closing all institutions and placing all retarded citizens in group homes because someone believes this is the way retarded people should be cared for.

Mentally retarded people are not all alike. Some are educable and can live in group homes or their own home - while others, who are severely retarded, need 24 hour care and supervision that can only be administered effectively in facilities such as an institution. It would be a cruel act to move these totally dependent individuals from the comforting confines that they have become accustomed to and move them to an environment where the level of care and safety can not possibly equal what they presently have and need.

We have a severely retarded daughter who is 32 years old and is residing at Southern Wisconsin Center in the state of Wisconsin. She has been there 25 years. She does not speak, has the mentality of a two year old, and is completely dependent for her safety and well being on the efforts of the staff responsible for looking after her.

We are not happy that our daughter is retarded and is in an institution, but we can sleep peacefully at night because we know our daughter is happy in her environment and is being well taken care of.

I am sure there are institutions around the country that I would not want my daughter in - but I believe the institutions in Wisconsin are above average and are a very acceptable and proven alternative to community placement and we therefore urge you to reconsider this bill calling for the closing of all state institutions for the retarded.

Very truly yours,

Mr. and Mrs. N. R. Gigliotta
12029 W. Hayes Avenue
West Allis, Wisconsin 53227

August 27, 1984

Mr. Roderick DeArment
Chief Counsel, Staff Director
United States Senate
Room SD 219
Washington, D.C. 20510

Dear Mr. Roderick DeArment:

On behalf of my daughter, Roberta, a resident of Southern Wisconsin Center, Union Grove, Wisconsin, I want to express VEHEMENT opposition to the passage of Bill S-2053, 'Community and Family Living Amendment of 1983.'

Roberta cannot function independently in any way whatsoever. Her simplest needs, from eating to maintaining simple cleanliness requires help. Her lack of communication only compounds her dependence. The treatment and care she has received at the above institution for the past thirty years has been more than adequate: it is equipped to fulfill her physical and emotional needs as well as giving parents of all the children like Roberta the reassurance and peace of mind they desire.

It is my sincere hope that as a representative of the people you will take our feelings into consideration. Thank you for taking the time to read this.

Sincerely,

Beatrice Goldman

1570 N. Prospect Avenue
Milwaukee, Wisconsin 53202

WRITTEN TESTIMONY

on

S.2053: COMMUNITY AND FAMILY LIVING AMENDMENTS

August 13, 1984, Hearing
Minneapolis, Minnesota

by Patricia Cullen
Greenbrier Home, Inc.

Members of the Health Subcommittee of the Senate Finance Committee:

Thank you for this opportunity to present written testimony on S.2053, The Community and Family Living Amendments. ~~I am~~ writing on behalf of Greenbrier Home, Inc., a large residential facility providing services to 165 adults who are mentally retarded.

Greenbrier Home, Inc. was the first halfway house in Minnesota to serve individuals with mental retardation. We "graduated" hundreds of individuals into smaller, less restrictive settings, and founded the Developmental Achievement Center movement in the state nearly 20 years ago. We have been proven leaders, changing with the trends as much as possible within the constraints set up by local, state and federal governments. We believe that many individuals presently being served in large institutions and ICF-MR facilities could be served better in smaller, community-integrated placements. In theory, S.2053 is a method of achieving greater community integration. In reality, the proposed legislation (S.2053) presents some major problems that should be addressed including cost containment, continuum of care, community readiness, and established timeline.

COST CONTAINMENT

There are no guarantees that S.2053 will result in an overall cost savings to the Medicaid program. The large, community ICF-MR facilities are generally older, with per diems in the lower end of the scale. For example, Greenbrier Home has one of the lowest per diem rates in the state, yet serves some of the more dependent individuals and individuals with behavior problems.

Most of the individuals remaining in the institutions in Minnesota require many services including intensive medical treatment and/or behavior management. The high costs for these same services in the community would certainly dispute the claims that ALL individuals can be served in the community within the constraints of the Title 19 Waiver. (Costs cannot exceed approximately $51.00 per day).

S.2053 would require a nation-wide transition of great proportions that would initially require a massive amount of capitol for administrative costs, building costs, and costs for the litigation which would no doubt ensue.

Minnesota is presently beginning to implement the Title 19 Waiver and has invested a great deal of time and money to assure its success. Passage of S.2053 could potentially "break the bank" in states such as Minnesota that are already moving forward in the development of options for individuals with mental retardation.

Alternatives to the present Medicaid system that are considered "cost saving measures" have been suggested by various task forces/organizations. Suggestions include:

1) Expansion of the Title 19 Waiver, and permanence for that concept. (Presently Title 19 Waiver is a non-guaranteed rule).

2) Separation of payments - payments for service from

payments for housing.

3) Public funding should follow peoples' choices to give them leverage over the systems that serve them. This would place residential and non-residential providers in competition with each other, and those with quality, cost-effective programs would "win-out".

These options should be explored before S.2053 is passed into law. Everyone agrees that Medicaid funding has escalated almost out-of-control and some action must be taken. We believe S.2053 will only add to the costs.

CONTINUATION OF CARE

Our facility has a large population of elderly persons with mental retardation. Some have lived at Greenbrier since it opened 20 years ago, and consider it their home. It will not be easy explaining to a 60 year old client and his family that a smaller setting is better than his present home. Granted, there are individuals who will be very appropriate for small community settings, but there are also individuals who are better suited for the socialization and development potential of the larger facilities.

We are concerned that individuals needing consistency with programs and services will not receive it during the transition period. As stated earlier, many individuals residing in the larger facilities have severe behavior problems. Changes in their structured program could only result in regression.

Movement out is a gradual process, and one that cannot be accomplished without established support mechanisms in the community. In reality, waiting lists exist today for less restrictive and specialized placements, some longer than 5 years. Facilities the size of Greenbrier would do a great injustice to the clients by pushing them out into inappropriate placements in order to achieve the "optimal" number proposed in S.2053. This would occur because of the long waiting lists at the more appropriate placements. These individuals, too, have rights and the process which would result from S.2053 could potentially violate these rights.

A better option would be to offer incentives to larger facilities to reduce their population. Greenbrier Home sponsored legislation at the state level to allow for bed reduction by changing fiscal disincentives. Legislation is still pending, but we have devised a long range plan for our clients that would provide an orderly transition and continuum of care once bed reduction is approved at the state level. Encouraging facilities to take a pro-active stance, rather than reactive, would be a much smoother method of implementing changes inferred from S.2053.

COMMUNITY (READINESS)

Logistically, metropolitan areas such as Minneapolis/St. Paul are not prepared to absorb the number of small dwellings that will need to be developed should the amendment pass. Recently there was great opposition to the opening of a home for 4 elderly individuals in a St. Paul suburb. And that was just one home!! Some state legislators have been resistive to any new housing developments in their district that would result from implementation of Title 19 Waiver. In Minnesota, with the Title 19 Waiver, new community placements need to be sought out, or developed. This task, coupled with the number of placements needed for the 2,300 left in state institutions and 3,310 left in community facilities of 15 or larger, is overwhelming at best. Where will all of these people go given the present housing shortages in the metropolitan areas? We do not have the answer to this dilemma, and it is a problem few have discussed in the debates on S.2053. We need to be confident that ghetto-like environments are not developed out of desperation.

ESTABLISHED TIMELINES

Our experience in Minnesota with the Welsch v. Levine Consent Decree has been that transition takes time. We have had over ten years to deinstitutionalize the state institutions, and have met the required number. However, many of those placements have been to the larger facilities, and the state is finding that it is becoming more and more difficult to place those still residing in the institutions. For this reason, the timeline of ten (and fifteen) years written in S.2053 may be unrealistic for the numbers that will be affected. (In Minnesota, using 15 or larger as the size factor, over 5,600 will be affected).

In addition, establishing legislation on the basis of how much time it will take to get to the "optimal level" when there has been no consensus on what the "optimal level" is may not be the solution. The legislation is not flexible enough to take into account the massive differences between the states in terms of numbers and services presently being offered.

Understandably, there are concerns at the federal level with the escalating costs of institutional care under the Medicaid program. That has been a state concern in Minnesota for the last several legislative sessions. The state has responded by involvement in the Title 19 Waiver program, placing percentage caps on rate increases, and halting the growth of additional ICF-MR facilities. We still have a distance to travel in Minnesota before we are providing equitable, quality services in the community in the most cost-effective manner; but we are heading in the right direction. We do not want our efforts and initiatives thwarted by legislation at the national level.

Numerous studies have suggested alternatives to the entire reimbursement system based on services, not facility size. A concept that should be considered is separation of payment for services from payment for room and board. All individuals do not need the same services, but presently they receive them anyway as part of the per diem rate.

Presently, facilities are penalized for cost effectiveness. Changes in the reimbursement system at the federal and state level should be made to provide incentives for bed reduction rather than "punishing" the larger facilities as S.2053 tends to do.

Again, some concepts behind S.2053 should not be "lost". There is a need for a national policy on services for individuals with mental retardation. Unfortunately, as stated, S.2053 is viewed by some as a barricade to development and growth, rather than a mechanism. There are some major problems with the legislation, as stated above, that should be addressed before Greenbrier Home, as a provider of services, can support the Community and Family Living Amendments.

Thank you for your time and consideration.

Patricia Cullen PC
Greenbrier Home, Inc.

H

Mr. Roderick DeArment, Chief Counsel & Staff Director
Committee on Finance, United States Senate
Room SD 219
Washington, DC 20510

8205 Gina Drive
Racine, WI 53406
August 25, 1984

Re: Bill S. 2053
Community & Family Living Amendments of 1983

Dear Mr. DeArment,

May we emphatically state that we are definitely against Bill S. 2053? We sincerely hope you will carefully consider the following, as we are very concerned!

We have a dear son, Paul Hagen, living at So. WisconsinCenter, only 20 minutes from our home. We value very much the tender loving care and excellent discipline he receives there. Every week we have him home for 1-2 days, and at times in the past it has even been from 7 days up to two months, during even some of the most difficult times. He is such a joy in many ways, loving to be part of our life with cooking, shopping, yard work, parties, attending Church and Sunday School every week, etc. He is "Uncle Paul" to six little ones who all love him dearly. He reads very well, and even teaches arithmetic, once for 2 hours to his little niece, as well as any professional teacher, and she loved it. He is an important part of our family and is doing very well, much loved by his brothers, sister, and sister in laws, and friends. Things were not always so pleasant. Since Paul was little, he was hyperactive and very difficult. So why is he in an institution? He needs very close supervision, because he is very active and creative, but often lacks the wisdom and logic. He is 23, nice looking, and lots of fun. Racine has what seems to be a fine group home, but Paul would very quickly find all sorts of ways to enjoy his new freedom, would become a real problem to neighbors and stores in the area, and would likely soon end up in an institution or jail. Besides there are always some people that would gladly tempt him with dope, alcohol, stealing or sex. He is such a willing spirit, that he's often happy to do what someone else tells him is right. As long as he has close supervision at the institution and at home, he listens carefully, and tries to do what he should, really with a happy heart, and surrounded by people who really love him and will tell him what is right, and are trustworthy. At one time he was in a group home, and enjoyed doing everything he wanted to, breaking rules, finally setting fire to his bed sheets, and being sent back to the institution. He was not ready. Another time, he was doing so well at Winnebago, and at home, they allowed him to come home for good. Paul was read his rights first, and he came home, determined to do everything his way, regardless of the consequences to others. He argued for hours at home for a key to the garage, so he could ride his bike whenever he wanted to, and kept calling emergency phone numbers to ask permission to do this, contrary to our instructions. But we were told by professionals that as an adult he had his rights. We were teaching him to ride his bike on the school playground, but he couldn't look up and didn't yet know the traffic rules very well. He took his bike without our knowledge, drove on the wrong side of the highway, and yelled at the drivers honking at him, "I have my rights!" A truck hit his bike, scraping his leg; the concerned driver was scared away by Paul's yelling. He took a cab to get a band aid from the hospital, and ended up at the police station, because he had no fare. He had been entering homes around town, demanding to use their phones, and frightening the residents. After two weeks of this kind of behavior, he was sent to Northern Colony where it took a solid year of intensive teaching before he came out of this terrible anger, and was taught gradually to respect the rights of others. They moved him into less restrictive environments as he could cope with them. They allow Paul, at So. Colony, to come home as often as he and we can manage. They take him and other residents on field trips, boat trips, to Milwaukee Brewers' ballgames, swimming, bowling, etc., on the $25 he gets from SSI. I've always wanted Paul to live at home when he's ready, but right now he has the best of two worlds. Why should we trade this wonderful arrangement for a group home where he is likely to get into all sorts of trouble, breaking laws, and alienating the many friends who have come to love him. He gets constant training when he's home, which works very well with the dedicated staff working with him at the Colony. Please do not take this away from us. If Paul is not cared for in an institution, he may someday have to be cared for in a prison. We need your help.

Sincerely, Mrs. Marcus W. Hagen

H

523 Alice St.
Wauwatosa, Wis 53213
Aug. 12, 1984

Dear Mr. De Armont

Concerning bill - S 2053
"Community & Family Living Amendments of 1983"

My son could not live in a community house, he is a non-talker and does not know enough to get out of the way of a car. I am opposed to this bill.

Southern Wisconsin Colony is a good institution and I do not think my son could adapt to what is proposed in this bill

Thank you your attention

Sincerely,
Mrs. Kathleen Hart

H

4795 N. Idlewild
Milwaukee, Wis.
53211

Dear Mr. De Arment,

My concerns are for the people who will be affected by the decisions made if bill S. 2053 is passed. What will become of those who need institutional help. There are many many who need skilled care. We as tax-payers owe loving and constant care.

Of all the waste in our country this is not the place to economize. I object to this bill and cannot see the advantages. If you send me a copy I'll read and hopefully will become more informed.

Thank you for all your consider-ations. May God grant you needed wisdom in guidance of your committee.

Sincerely
Sarah Hanna

8-23-84
H

Mr. Robert DeArment
Chief Counsel & Staff Director
Committee on Finance
U.S. Senate Room SD 219
Washington D.C., 20510

Dear Mr. DeArment:

We are parents and guardians of a developmentally disabled 35 year old son who has resided at So. Wi. Center for the past 19 years. His welfare has always been of utmost concern to us. Therefore, we are extremely fearful of the consequences of S-2053, Community and Family Living Amendment. We do not accept ARC recommended changes to this bill advocating an 85% withdrawal of Federal Medicaid funds from State D.D. Centers. We advocate no withdrawal. We feel that So. Wi. Center provides excellent care and services. By diverting medicaid funding to community facilities, the quality of care in institutions will, of course, deteriate drastically. Integration into communities is not an appropriate goal for all the retarded, although some may benefit. There is, and always will be, a need for good institutions staffed with skilled professionals. We firmly believe that our son's needs cannot be met in the community. We are aware that the past and present history of group homes is such that the burn-out of houseparents is prevalent resulting in an unstable "home atmosphere". Too, we feel that not enough emphasis will be placed on the monitoring and supervision of many community placements due to prohibitive costs. Studies indicate that services provided at the Wisconsin State Institutions for the Developmentally Disabled cannot be duplicated in the communities at a lower cost.

Thank you for any consideration you may give this letter.

Sincerely:
Mr. + Mrs. Philip W. Harper
11907 Timberline
Hales Corners - Wi. 53130

Copies sent to -
Sen. Durenberger, Paul Marchand, N.A.R.C.

JOHN C. HEFFELFINGER, M.D.
555 Milford Street
Watertown, Wisconsin 53094

Telephone: 261-8706

August 20, 1984

Mr. Roderick A. DeArment, Chief Counsel
Committee on Finance
Washington, D. C. 200510

Dear Mr. DeArment:

Re: Medicaid Funding, S. 2053
8-13-84 Hearing, Minneapolis

The hearing annoucement arrived on August 3 at my home and, of course, I did not read it until evening and, thus, too late to call. My statement will be as brief as possible. I do however have a question. Which governmental agencies are responsible for the late arrival of this information and thus denied me an opportunity to respond in person?

My practice, whether at a university, in private practice or when helping at a large DD institution certainly gives me a broad medical perspective of institutional, private practitioner, community and parent's view of the problem. I also serve on a developmental disability state planning program to evaluate and propose budget needs for this group. In addition, I serve as a co-liaison person for our community partnership effort on disabilities (National Organization of Disabilities).

Community placement is the ideal for a great number of developmentally disabled, be it in their own home, foster care or group home, but not all parents' homes, group homes or foster care homes are ideal.

Although there has been an increase in the number of better trained personnel in community facilities, there has to be a major step taken to equal the quality of care of many of the larger institutions.

Until you can provide safer (from abuse) homes, more and better programming in the home community, adequate medical care for their multiple problems and community support for these people, I cannot support this legislation in its present form. Many individuals are being transported to large facilities for programming, education, work, etc., that aren't any better or as good as some of our present institutions. Bus travel, especially for the handicapped person, is not as safe as residing in a facility who are able to reach their programs in five or ten minutes instead of hours of travel.

Deinstitutionalization is a magic word, but some community facilities are more "institutionalized" than some much larger units. There are good and bad community, as well as larger facilities. Nursing home care will always be needed by some, or some special facilities for the psychiatric, behavioral, severe seizure or metabolic problems.

The return rate from community to a larger facility ranges from a low of 10% to a high of 50%. This includes the returnees from the highly skilled, university-affiliated programs. Where will they go? Will it be similar to what has happened in the mental health field with "street people," no care, no home? Enclosed is a reminder of what has happened in the mental health field.

I believe the cost of providing the same hourly contact by professionals will be more costly at community-based programs for the same level and quality of care.

I don't know the answer to this question, but maybe you do. What was the percent of increase of the total expense, including buildings, staff and perks, our departments of defense and our congressional organizations compared to Medicaid over the 1973-1983 period?

There are some parents who could/can provide full medical care for their child and a larger number of parents who could provide some sliding percent of the medical care costs who now receive full Medicaid funding.

I appreciate the opportunity in discussing this with you. Blessings in your work and may the Lord guide you in this very difficult decision.

Sincerely,

J. C. Heffelfinger, M.D.
Medical Director

JCH:dag
Enc.

cc: Senator Dave Durenberger

MILWAUKEE JOURNAL - June 19, 1984

Many homeless are mentally ill, Heckler says

Staff Correspondence

Philadelphia, Pa. — The chronically mentally ill represent up to 50% of the nation's homeless, and many of them have the process of "deinstitutionalization" to thank, Secretary of Health and Human Services Margaret Heckler said here Monday.

Speaking to the US Conference of Mayors, she noted that in the early 1960s there was a nationwide shift to get the mentally ill out of large public hospitals and into some form of community care, the so-called deinstitutionalization process.

It began as "a philosophy of hope," Heckler said. "But in fact, for many, it has become a program of abandonment for our fellow citizens."

"It is painfully obvious that the dollars saved by the state by reducing their census in state hospitals did not follow these clients into their communities," she said.

"In addition, states began to close their state institutions' doors to this vulnerable population.

"Many state laws actually foster homelessness by prohibiting the involuntary commitment of the mentally ill unless it can be proven that they cannot take care of themselves. Typically, the courts have viewed homelessness as a lifestyle of choice and not evidence of an inability to care for themselves."

"We must aim at reducing the size of the homeless population by providing permanent relief."

...

MRS. M. J. HEISMAN
1041 EVANS STREET
OSHKOSH, WISCONSIN 54901

Aug. 16, 1984

Mr. Roderick Dekrment
U.S. Senate
Washington, D.C.

Dear Mr. Dekrment:

I am writing in regard to the bill, S. 2053, Community & Family Living Amendments 1983 which affects me and my severely retarded son immensely. I am 80 years old disabled and have had peace of mind while my son who is 46 years old received excellent care and training at Central Wis. Colony in Madison, Wis. Any change in his environment would cause me great anxiety and worry.

Please do not allow this bill to pass.

Yours truly,
Mrs. M. J. Heisman

RANDY JOHNSON
COMMISSIONER

PHONE
612-348-3088

BOARD OF HENNEPIN COUNTY COMMISSIONERS
2400 GOVERNMENT CENTER
MINNEAPOLIS, MINNESOTA 55487

1984 AUG 30 AM 9:43

August 24, 1984

The Honorable Dave Durenberger
353 Russell Senate Office Building
Washington, D.C. 20510

Dear Dave:

Thank you for the invitation to speak at your recent hearing on S. 2053. I was unable to attend the meeting, but I would like to submit for the record some analysis done by Hennepin County staff.

I know you are aware that Hennepin County has committed considerable resources to developing alternative models of service for our mentally retarded citizens. Although the waiver to fund home and community-based services by means of Title XIX (Medical Assistance) is in its infancy here in Minnesota, we are moving ahead as quickly as possible to move clients who no longer need residential care in an ICF-MR to more independent living situations.

We are very pleased with your interest in containing costs while improving the continuum of care of the mentally retarded, and I hope the attached comments are helpful.

Very truly yours,

Randy Johnson
Commissioner

RJ/lw/191
Attachment

cc: Kevin Kenney
Mike McGraw
Carol Hood

AUG 22 1984
SOCIAL SERVICES

HENNEPIN

DATE: August 21, 1984
TO: Kevin Kenney, Associate County Administrator
FROM: Mike McGraw
Carol Hood
SUBJECT: Comments Regarding Proposed Legislation-S.2053
Community and Family Living Amendment

The proposed legislation affects Medical Assistance funding of residential placements of severely disabled individuals. When a residential placement is necessary, this amendment encourages the use of small family-like or community settings by the use of incentives and gradual withdrawal of Medical Assistance payments for "institutional" care.

Philosophy

1) There is a commitment from all levels of government to make more "normal" living environments available for the mentally retarded. However, the development of non-institutional alternatives is seriously hampered by the cost containment philosophy of the legislation. This amendment addresses the need to raise staff salaries in community facilities and yet there is no mechanism to pay for it. Community living arrangements are often more expensive than average institutional costs for difficult clients.

2) I am not convinced that all facilities over 15 beds should be phased out. Depending on the facility, the client's needs, etc., a larger residence may be the most appropriate choice for a client. The 85% withdrawal of funds proposed by the ARC/US may be an effective alternative.

Individual Client Eligibility

1) The age limit of 21-65 years does not seem desirable. This standard could apply to all severely disabled individuals with some provision for cost of care payments for children.

2) The ARC/US has suggested that the SSI definition of developmental disability be used so that all developmentally disabled individuals who quality for SSI would be covered under this legislation. Consistency across programs would simplify programming.

3) There is a two-year limit on institutionalization. Some clients may not be stabilized during that period. The assumption probably is that services should be developed in the community to meet the individual's needs during that time period. Is MA willing to fund whatever is needed to maintain the client in the community?

4) The family and individual must be notified 60 days prior to placement in a family or community living arrangement. Provision needs to be made for emergency placements.

Provider Eligibility

1) The impact of the census data requirements on family living situations could potentially diminish already limited resources.

2) The language pertaining to standards and requirements for licensing, programming, monitoring, and evaluation is very limited. Perhaps additional specifications will be developed by each state.

Eligible Services

1) This amendment is more flexible than current legislation regarding the types of services that can be funded. A broader range of services is available to support the client in the community. This flexibility provides for more effective case management.

Impact on County

1) The requirements for the implementation agreement seem reasonable.

2) There are some reports that are required every six months when annually seems adequate.

3) The ARC is proposing a maintenance of effort with non-MA funds if the county cannot/does not develop eligible facilities under the timelines proposed. This could be quite expensive.

4) There are incentive and penalty clauses for compliance and non-compliance with this legislation. Either one or the other should be sufficient.

Summary

The funding impetus provided by this amendment will speed up the change from institutional to community-based residential facilities. Flexibility and funding need to be ensured so that individual clients can receive appropriate services. Also, the language supporting "specialized vocational services" is significant for this is a key area in the overall service continuum.

MM/pr

cc: Mike Weber
    Carol Hood

August 24, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, D.C. 20510

RE: Bill #S-2053
Community and Family Living Amendments Act.

I am writing you regarding the above Bill #S-2053. May I please take a few minutes of your busy day to state how this Bill could affect my daughter Carol Ann Herbst at the Central Wisconsin Center, Madison, Wisconsin.

Carol is blind, deaf and severely retarded, she is totally dependent on someone for every move she makes, she needs medication daily and therefore medical help is needed at all times. She is my precious daughter and I am strongly against the above Bill. PLEASE let these children of God stay in their present surroundings with the loyal and dedicated help available.

Thank You.

Yours very truly,

Mrs. Marjorie P. Herbst

Mrs. Marjorie P. Herbst
520 N. Park Blvd.
Brookfield, WI 53005

✓ This letter to be considered as Written Testimony for the hearing on S.2053 which was held in Minneapolis August 13th, 1984 by Senator Durenberger.

3925 - 83rd Place
Kenosha, Wisconsin 53142
August 21, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

Mr. DeArment:

I understand that Senator Chafee has a bill, S2053, Community and Family Living Amendments of 1983, relating to State Institutions for the Retarded. This bill would require all retarded persons to live in the community in small group homes; no person would be allowed to live in an institution more than two years during his lifetime. Medicaid funds would be withdrawn from state institutions.

I would like to speak from my experience. My brother is severely retarded and has lived at the Southern Wisconsin Center for 28 years, since he was 12 years old and my parents could no longer care for him at home. He was brain-damaged, had seizures, and was at the mental level of a two-year-old.

At present, because he swallows whatever he can get, including bandages, feathers, cigarette butts, and more, he must wear a helmet and screen over his face besides being under constant close supervision. When he was hospitalized, he needed 24-hour surveillance. He does not understand much.

There is no practical way for him to be at home or in a small group home. To consign him to one would be to guarantee further surgery, hospitalizations, and untold misery for one already severely afflicted.

There are many more like my brother and many who are worse off. It is a sad but certain fact that they need institutional care for life. The state institution is providing this sorely needed care. To eliminate it would cause havoc.

I ask for consideration of the experience of those who have cared for these unfortunate retarded people. Community group homes are good for some and these are placed in them. For others, it would be impossible to give practical care outside an institution. Please do not lock those concerned into impossible laws and restrictions. Instead, allow them discretion to do what is best for all concerned.

Mr. DeArment, please consider my letter as Written Testimony for the hearing on S2053 which was held in Minneapolis on August 13, 1984, by Senator Durenberger.

Thank you for your consideration.

Yours truly,
Rosemary Hunkeler
(Mrs.) Rosemary Hunkeler

H.H.B.32nd
A.P.O. New York 09175
14 August 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

Bill S. 2053
Community & Family Living Amendments of 1983

Mr. DeArment;

We are an Army family now being stationed in Darmstadt, Germany. We have a 10 year old son in the Southern Wisconsin Center for the Disabled. Aaron has been retarded since the age of 22 months.

Aaron has been in the Southern Wisconsin Center ever since he was three years old. He is blind, deaf, and is mentally the age of a three month old child. Children like Aaron need stability in their lives. I have done research myself when I looked for a place for my son and I found out that these "group homes" do not have it. In order for him to reach his full capacity in life, he needs many types of therapy that only a state funded institution can offer. As an American serving his country for 18 years, I feel that you are taking my sons rights away from him.

It is very difficult having a child like this; but, it is even worse being overseas and worrying what your childs future is tomorrow. As you can guess I am strongly AGAINST this bill.

I ask that this letter be considered as Written Testimony for the hearing on S. 2053 which was held in Minneapolis on August 13th, 1984 by Senator Durenberger.

Sincerely,

SFC Fred Huebner

SFC Fred T. Huebner

Aug.I4/I984 J

Dear Mr.DeArment,

Being a parent of a blind and retarded child is realy heart breaking,and I wanted the best for my daughter and was unable to care for herbecause I had a baby,and have been ill fortwenty three years now.If I had the money I would have gotten home help,and kept her home with me.I love her very much,and if you have any children of your own you'd know my feelings.When Susan was born I wanted to do away with her and myself,because of the hospital's misstakes my daughter is the way she is.Susan could never be in a Family Commitee setting,she needs help twenty four hours a thats why she's in an institution.If it would be for her best interest I'd be all for it.I hope and pray that the bill S.2053 will not be passed,and you'll think about it very hard before anything is done. Please say no to that bill.

Sincerely Yours

Annette Jacobson
Box 209
Silver Lake,Wi.53170

Annette Jacobson

Susan Byron's mother

P.S.I was told that there wouldn't be any medicial help for her,if the bill is passed,I think thats terrible. Susan was 2pounds at birth and placed in an incubator,and was given to much oxygen and became blind and retarded.

4040 Washington Road
Kenosha, WI 53142
August 27, 1984

Mr. Roderick DeArment
United States Senate
Room SD 219
Washington, DC 20510

Dear Mr. DeArment:

This letter is being written as written testimony against Senator Chafee's bill to close all state institutions for the retarded.

My son, Bruce, is in the Southern Colony Center in Union Grove, Wisconsin. I am not in favor of him being placed in a group home as I've already had some bad experiences with him being placed in two different homes here in Kenosha.

While he was in these homes, hebeat the group mother and father up and was placed in the psychiatric ward twice before he was placed in the Brookside nursing home here in the Kenosha. He also broke an elderly lady's hand by slamming the door on her. The violence was caused by seizures, which he had never had when he was at Southern Colony.

Bruce is back at Southern Colony now and is doing very well. He hasn't had a seizure once and seems much happier in that environment. He doesn't seem to be able to take changes of any kind.

He's so happy and content at Southern Colony. It's a shame these handicapped people have to be moved around at such great cost to the patients, their families, and the government, in terms of both happiness and money.

Thank you,
Arlys Jermstad
Mrs. Merlin Jermstad

Hearing August 13, 1984 in Minneapolis on Medicaid funds to care for the mentally retarded and developmentally disabled. (S.2053 and other options)

Testimony submitted by John Johnson, 175 E. Thompson Avenue #9, West St. Paul, Minnesota 55118 phone: 612/451-9151.

I was placed in an institution in 1934 when I was five years old. I lived in Faribault State Hospital, Cambridge State Hospital and Owatonna School until 1972 when I moved to Orvilla, a community residential facility in Eagan. I now live on my own in an apartment in West St. Paul and work at Rainbow foods.

The 34 years I spent in institutions were very boring and unpleasant years. There was no schooling, I just sat around all day and sometimes saw a movie which was picked out by the staff. There was no privacy -- I bathed with staff watching and slept in a large room filled with other men. My mail was opened, I was not allowed to use the phone or go out on my own. The doors were locked. Everything we did was timed. The men and women were seperated and we were not allowed to have any girlfriends - not even allowed to talk or write notes to the girls. Men who left the institution were often sterilized whether they wanted to be or not.

I now live on my own in the community. I can go out when I want with who I want. I can chose my own recreation, go on trips, see my family. I have a job and my own money. I went to school at night and took classes in reading, writing and math.

I think young people should live in the community, not in institutions. so they can learn and make their own choices. If you really want to know what its like to live in an institution you should go live there - you won't like it!

Statement made by John Johnson, typed by
Marianne Reich, ARC/Dakota County
33 E. Wentworth Ave #105, W. St. Paul, MN 55118

[illegible]
Traverse City, Mich.
5-13[illegible]

[illegible] [illegible],

[illegible] writing a letter regarding the [illegible]. I want to consider [illegible] [illegible] [illegible].

[illegible] opposed to the [illegible] of [illegible] [illegible] [illegible] [illegible]. to community and family [illegible] [illegible] 1983.

My [illegible] is one that is retarded. & getting [illegible] he is now in an institution. That is not the only place where he could get [illegible] [illegible] and [illegible] the [illegible]. The large place knows [illegible] to deal with these people some are worse than he is. I don't think they would get [illegible] [illegible] of small group homes. Let's give these children and people of God a chance

[illegible]

[illegible] Senators [illegible] figure out a way, that [illegible] some one in that will be [illegible] some [illegible] that [illegible] that [illegible]

Thank you [illegible]

[illegible]

Frances [illegible]

[illegible]

August 27, 1984

Senator Robert Dole
Roderick De Arement
Committee on Finance
US Senate
Washington, DC. 20510

Gentlemen:

Please register my support for S2053 the Community and Family Living Amendments and its propsed changes of an 85% withdrawal of coverage from Nursing homes over a 15 year period. Enter this as Testimony to the Minneapolis Hearing.

I have a retarded brother age 23 who needs residential and vocational services in the community. My parents need respite care. There must be planning for my brother's future.

I have recently completed my Master's Degree thesis on Home care and Community Programs as Alternatives to Institutional Care for the Developmentally Disabled and the Elderly and am convinced that more normalized and appropriate services could be provided in the community if more medicaid dollars could be directed to community programs.

I am currently employed in an administrative position in an area Nursing home and am aware of value to retain some medicaid dollars for nursing homes but more importantly the value of expanding the use of medicaid dollars to community programs.

I urge passage of S 2053 with the above changes.

Very truly yours,

James D. Keller

James D. Keller

3353 A. North 53rd Street
Milwaukee, Wi. 53216

August 25, 1984

Senator Robert Dole, Chairman
Roderick De Arement, Chief Council &Staff Director
Committee on Finance
United States Senate
Washington, D. C. 20510

Gentlemen:

I wish to register my support of S. 2053 the Community and Family Living Amendments of 1983 and urge its passage. I would support the suggested changes of an 85% withdrawal of Medicaid funds from nursing chare facilities over a 15 year period rather than the 100% as proposed in the original S.2053. I further request that htis letter be included as Testimony for the Regional hearing held in Minneapolis on August 13, 1984.

As a parent of a substantially disabled retarded son, age 23, I am aware of the lack of communtiy programs and services for my son and the the retarded sons and daughters of my friends.

As a former 3 term State President of the ARC-Wisconsin 1976-78 I have advocated for appropriate programs and services.

I was made succinctly aware of the void in community services when my own son graduated from public school and as on a WAITING LIST for community vocational programming.

I labored the past 3 years in my community for essential programs and services (see sample letters) and made appearances before significant community political bodies and leadership.

Government will spend $45,000 to house a substantially disabled person in the Centers for the Developmentally Disabled $15,000 in a nursing home, but have WAITING LISTS for essential community services. Medicaid dollars for family home and community based services are necessary and a phase out of the costly expenditures for institutional care that sap the needs of the majority of substantially disabled persons. Prudent public policy dictates a change in the present system.

Turn this outrageous situation around- put medicaid dollars to community programs since most substantially disabled persons live in and wish to be in the community. I urge passage of S 2053 with the above changes.

Very truly yours,
Elaine A. Keller
Elaine A. Keller (Mrs. Donald)

4262 North 83rd Street
Milwaukee, Wisconsin 53222
414-466-3494

DEPARTMENT FOR HUMAN RESOURCES
COMMONWEALTH OF KENTUCKY

BUREAU FOR HEALTH SERVICES

August 28, 1984

Senator David Durenberger, Minn.
United States Senate-Committee on Finance
Dirksen Senate Office Building, Room SO-221
Washington, D.C. 20510

Subject of Hearing: MEDICAID CARE
FOR RETARDED

Dear Committee Members:

The Oakwood Training Center, located in Somerset, Kentucky, is one of the newest, most modern facilities for persons with mental retardation in the country. At our most recent licensing survey, we are proud to announce to you that we were awarded a Superior Rating from our surveyors - one of the few in the state for long-term care facilities.

We are constantly upgrading our facilities and the individualized programs for our residents. We work closely with both parents, other agencies, and this community and we are satisfied that our programs are of the highest possible quality for programs of this type. Our parents, surveyors (including representatives of the Medical Assistance Program), community people, and others, all feel we have quality programs that are safe and secure for those we serve.

Our parents, our Chamber of Commerce, and primarily our professional staff have read the Senate Bill 2053 and are extremely distressed with the proposed plan that would close this and similar facilities. While we all believe in the availability of an array of services for persons with mental retardation, both in facilities and communities, we believe too that there is a segment of this great countries population who will be and are better served in facilities than in existing or proposed community programs.

Some of our professional staff have been working in the field of mental retardation in excess of twenty (20) years and have had the opportunity to become familiar with this population first hand. We have learned with the onset of many different community programs that these programs, by and large, are not as organized or well-staffed as facilities just by virtue of their location. Some smaller communities in this state cannot draw on professional and certified staff because of their location, whereas, at facilities such as ours, professional staff take advantage of the opportunity to work with other professionals utilizing the team concept in close proximity to more needy and available consumers of services.

Often with community programs, assessments and training priorities are not delineated and therefore quality services are not always available to those in need. Coordination by specific persons is not always detailed.

Community programs, because they must be spread throughout a community, cannot offer the constant monitoring as facilities are subject to by the closeness of the residents and by the regulatory bodies.

Many times, the concept of "least restrictive environment" is tossed about as a "given" with community programs. This term, however, of "least restrictive environment" should be regarded as the structure in which the individual can most adequately function while retaining his security and stability. With the advent of community programs, the facilities predominantly house the severely and profoundly retarded and/or behaviorally disordered individuals. As a general rule, the severely and profoundly retarded possess secondary handicaps with speech and language disorders and physical impairments being the major handicap. Because of the secondary handicaps, these individuals require a greater array of services than higher functioning persons with only mental retardation.

Most facilities function as a small community with in-house treatment and leisure services. The environmental ecology and physical plant have been structured to be as hazard-free as possible in order to allow the retarded living therein freedom of movement in accordance with their individual ability. The total environment is structured for the needs of the inhabitants rather than for a normal individual who possesses the ability to structure and adjust his own environment. The facility environmental structure provides activities such as canteen services, movies, playgrounds, swimming pools, and recreational activities wherein many of the inhabitants can utilize these services with only limited supervision. In order for these individuals to live in the community, they would need constant supervision, escort outside of living quarters with no opportunity for experiencing minimal independence. In other words, they would not be able to go to the shopping center for a soft drink or to the school playground without supervision and escort. For this type of individual, the community serves to be a restrictive environment.

In many incidents, a community placement is a MORE RESTRICTIVE environment than an institution. Therefore, it is imperative that the concept of "least restrictive" be applied to individual needs rather that the general needs of the "normal" population.

As professional staff, we have had verbal and written testimony from concerned parents who have attempted to keep their child in their own home without success. All of these are parents who, like other parents, have their child's best interests at heart and who would like to have their children at home; but due to age, behavior problems, incompatibility, etc., their child could not remain in their own home.

These parents feel that a facility where their child is free to reside with their peers is the best environment for their child and much better than in an environment where they are not accepted and are often ridiculed as parts of our society are wont to do.

Many of these same parents have heard horror stories about some retarded persons who are mistreated, taken advantage of, not cared for, in community settings. These less stable and less secure environments horrify them.

Our facility currently has a population of approximately 85% severely and profoundly retarded persons. Over the years, our population has gradually changed from mildly and moderately retarded to severely and profoundly retarded persons, many with accompanying behavior problems. Many persons with mental retardation who present behavior problems are not tolerated in the community and some communities feel unable to deal with this type person. These persons make up a large percentage of our population. Even areas where there is supposedly excellent training and qualified staff, there are problems with behaviors as well as secondary handicaps. Often certified staff is just not available and would be impossible to provide to each tiny community requiring special services.

When we first began to place some of our residents into the community, there was loose talk about community care being less expensive than facility care. Most recent statistics do <u>not</u> bear this out. We later learned that in most cases, community care is MORE expensive when you include auxiliary service costs usually provided for in facilities. Community care being less expensive is a MYTH.

Our residents are provided with more and better quality services than would be available to them in their home or similar communities. While there may be some institutions that do not or cannot provide adequate services for its residents, our facility is reputedly one of the finest in our nation as acknowledged by our licensing body when they awarded our Superior Rating.

While we do feel that communities can serve some higher functioning persons with mental retardation, in our professional opinion, there are many persons who can and should only be provided services in a good facility such as ours. To terminate funds at facilities for those who desperately need our services would be criminal.

We therefore support the DEFEAT of S. 2053 which was designed to eliminate appropriately individualized services for a large segment of our national population needing the Medicaid dollar in order to survive and to survive well above what they could get in some communities.

Sincerely,

EWilson

Elaine A. Wilson, MSSA, ACSW, QMRP
Liaison Coordinator
Oakwood
South Highway 27
Somerset, Kentucky 42501

EAW/vr

cc: Oakwood's Parent Association, PROOF, Inc.

August 10, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 21)
Washington, DC 20510

Dear Mr. DeArment:

Please use my enclosed letter as a Written Testimony for the hearing which was held in Minneapolis, Minnesota on August 13, 1984 on the Bill S. 2053.

I do not how to make myself heard any louder or stronger but I do know I do not want funding taken away that will harm my child. Bill S. 2053 should not be passed.

Sincerely,

Mr. Edgar C. Keske
3787 S. 69th St.
Milwaukee, Wisconsin 53220

Turn down Bill # S 2053 Community and Family Living Amendments Act

My daughter Heidi has been a resident at Southern Wisconsin Center for the Developmentally Disabled, Union Grove, Wisconsin for the past 21 years. She has received excellent care in many, many areas not only in providing adequate surroundings to live in, but immediate medical help for seizures, malformed spine correction, immediate medical help to prevent her from too seriously injuring herself in head banging instances. She has had on the presises schooling for dexterity and communication skills as she is also nonverbal. The staff are constantly having to monitor her for needs. Medical problems are always present in one form or another - eye infections, spine abnormalties, dental care etc, etc. Heidi has self abusive problems when changes in life style are made as well as when demands for constant companionship, activity, and recognition of achievements are not met. Heidi is diagnosed as severly mentally retarded.

Close institutions and open Group Homes -- NO WAY.

There just is no way a group home can provide the level of care, teaching, medical attention, the 24 hour alert care, the tender, loving care she now receives.

The only thing a group home can provide is an atmosphere in which she will regress in all ways: medically, physically, and emotionally.

Don't do it to her and her friends. Don't let Bill # S2053 pass.

Do you really want to do something to improve our world? Visit Southern Wisconsin Center. It is located 25 miles southwest of Milwaukee. Follow their example and set up beautiful areas with excellent staffs and you will make many people very happy.

Sincerely,

Edgar C. Keske
3787 S 69th Street
Milwaukee, Wi 53220

August 10, 1984

Aug. 24-1984
3723 Cth P
Cross Plains Wi.
53528

K

To Whom It May Concern,

I'm writing in response to the bill S 2053 on "Community and Family Living Amendment of 1983."

I have two children in Central Wisconsin Center at Madison. The oldest, Tim is now 19 years old and can't do anything in the self help skills, in fact he barely sits up alone. He also has daily seizures. We were told he wouldn't live to be three years old.

When Tim was found to have problems the doctor encouraged us to have a second child. Along came Greg who was doing fine until he was about one year old, he started having seizures, But seemed OK. The next year I had a third child Steve who is "ok" at 16. When Steve was born Tim was placed at Central Center. As time went on Greg showed more signs of retardation, I kept him at home till he was 11 years old. I had become a single parent and had to work full time. I couldn't handle the care he needed, I found it harder and harder to hire sitters. He was very active and very strong. He has never spoken a word but is now 6'2" and weighs about 160 lbs.

They both have been cared for very well and require a constant routine.

I visit them often. I also worked with the Dane County Special Education for a year and am aware of the routine being the same means a lot to all of them.

It makes me very upset to hear of the changes they are talking about. The people that work in these centers are trained!

When you think of voting for this bill for all children I'd like to hear that you spent a week with these children before you making your decision final.

Thank you

Janet Kitsemble

R

Kenosha, Wisconsin,
August 20, 1984.

Dear Mr Roderick De Arment:

I strongly oppose Bill - S 2053, Community and Family Living Amendments of 1983.

I am the mother of James Knudsen, age 43. and Joseph Knudsen, Age 39.

For 27 years James and Joseph have resided at the Southern Center, Union Grove, Wisconsin. They are content and happy with their surroundings. It is their home. James and Joseph are severly retarded and need total care. The dedicated employees and supervision is excellent at the Southern Center. I am a regular visitor.

The State of Wisconsin is well known thru out the United States for having the best facilities for medical and personal care for the severly retarded Children. We must keep Southern Center open for them. Please dont break up the Childrens home.

Sincerely Yours,
Mrs Margaret Knudsen
3811 - 128th Avenue
Kenosha Wisconsin
53142

August 24, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, D. C. 20510

Dear Mr. DeArment:

This letter is in reference to bill S.2053, Community & Family Living Amendments of 1983. It is my understanding that this bill, if passed, would withdraw all Medicaid funds from all state institutions for the retarded over the next ten years; and (2) place all retarded persons into the community in small group homes.

I am a parent of a retarded child who resides at the Central Wisconsin Center (CWC) in Madison, Wisconsin, and I also am a group parent to the retarded working at the same institution. My daughter has lived there 3 years and I have worked there for 1 year.

I am writing because I am concerned for the future of my daughter and others in state institutions. I do not believe all the retarded belong in group homes in the community. I believe the severely and profoundly retarded can receive the best care in a state institution. These people have severe physical, mental, and emotional problems and their needs can be best met in an institution where many services are readily available. There is a hospital, necessary medical equipment, and specialized staff at the disposal of the residents. These would not be readily available in a group home. I do not believe that changing the environment to a group home will better or equal the quality of care to these people.

I therefore ask that you take a stand against bill S.2053.

Sincerely,

Roger Kruk

Roger Kruk
3137 Milwaukee St., #3
Madison, WI 53714

12900nGremoor Drive
Elm Grove, WI 53122
August 16, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

Re: S2053, Community & Family Living Amendments of 1983.

We are writing to express our strong opposition to this measure, as parents of a profoundly, multiply handicapped son. It would have serious adverse effects on our son Robert, age 25, who has resided at Southern Wisconsin Center in Union Grove since 1968. We also believe it would harm hundreds of other residents of this excellent facility, forcing them to relocate in facilities which do not now exist and would therefore have to be built and staffed -- at an incalculable cost in both dollars and human efforts.

Prior to Robert's entering Southern Wisconsin Center (SWC), we tried several alternatives: extensive physical and occupational therapy at Easter Seal, evaluations at several clinics, eye surgery (unsuccessful), special classes for the handicapped, and more. Despite all these efforts, Robert today is still blind, and less than 1 year old developmentally. He does not walk or talk, and is not toilet trained, despite the best efforts of a series of highly qualified and dedicated professionals at SWC and elsewhere. We did not just institutionalize him without trying every possible alternative.

When he entered SWC, we were unable to keep him happy at home or care for him satisfactorily. At SWC he attended classes until he became 21, and would have continued had he shown any progress. He receives hydrotherapy twice daily, recreational therapy, continual observation by medical personnel, and loving care by staff members. He benefits from frequent consultations among the professionals who work with him, including a psychiatrist. Robert's case, as well as those of all SWC residents, is reviewed at a staffing every year, in which parents are invited to participate. Robert has required hospitalization occasionally for self-inflicted minor injuries, and has received excellent care at the fine hospital operated by SWC.

We no longer bring Robert home for visits, as we formerly did about once a month. These visits had become increasingly traumatic for him and for us, so now we visit him at SWC regularly. He seems to enjoy being with us, but it's just as obvious that he loves the attendants who care for him. And they love him. Our visits are made without advance notice, and we always find the cottage he lives in in immaculate condition.

We have visited smaller community-level homes caring for the retarded, and frankly those we have seen fall far short of what SWC offers -- in physical facilities and certainly in professional staffing. Perhaps other states don't have facilities such as Wisconsin offers; we know from personal experience that when we lived in Illinois their facilities lagged far behind Wisconsin's. But why force Wisconsin and other states to close excellent facilities -- and duplicate them at horrendous expense -- just because some states have lesser facilities?

Please, we beg of you, do everything you can to see that this bill does not become law. It would do an incredible disservice to our son Robert and hundreds like him at SWC, and it would be an incalculable unnecessary expense to taxpayers.

Sincerely, James A. Kuehn
Mary A. Kuehn
James A. Kuehn and Mary Ann Kuehn

L.

August 9, 1984

Mr Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
U.S. Senate - Rm SD 219
Washington, D.C. 20510

Dear Mr DeArment

This letter is being written in reference to Bill #S 2053 titled "Community & Family Living Amendment of 1983"

This bill would endanger the life of my son Lawrence who is a resident at Southern Wisconsin Center. He is 37 years old with the mental capacity of 4 1/2 years of age. He must have the type of care that he is receiving so as not to [illegible] not to injure himself. He also needs his pills. He could never live out in the community.

I am bitterly against any

Pg. 2

Change away from the fine institution that he is happy in and doing exceptionally well in.

Please listen to those of us who know and care for our loved ones.

This bill must not pass.

Sincerely,
(Parent & guardian) Virginia J. Larson
120 W. Lee St
Stoughton, WI 53589

Aug. 28, 1984

Mr. Roderick De Arment,

Bill S. 2053 - "Community & Family Living Amendments of 1983".

My daughter has been living at Southern Wisconsin Center for the Developmentally Disabled, Union Grove, Wis., for 2 years and 4 mo's. She has mental retardation, Cerebral palsy, & epilepsy. She lived at home for 12½ years, before the big move to S.W.C. She adjusted so fast, and is so happy. And me? I'm still trying to adjust. For you see, she's my only child. I think back on how frustrated she use to be, and now so content. And I think how selfish I was for 12½ year, to keep her in my world, only because I believed it was the right thing to do.

I strongly oppose this bill! When was the last time you were in an institution? Or haven't you been there yet? There couldn't be enough group homes, & where are you going to find the people to staff them? What about the Doctors & Nurses who are at institutions, are they also going to be in the group homes? What about the Retarded themselves? How are they to cope, in a world that doesn't understand them, just because a bill says they have to.

What if the Bill was reversed? All retarded people must live in an institution! Then what? Would you still be for it?

Mrs. Nancy J. LaPoint

August 28, 1984

To Whom It May Concern: Mr Roderick DeArment

This is the second letter I am writing in regards to Bill S-2053.

I am the parent of a severely retarded boy who is now a resident at the Southern Wisconsin Center. I have some deep concerns about his future well-being and happiness.

My son has been at the center for 17 years now. He is very loud and constantly hollers "OK". He is one of the many children at the center who would not be able to function in a group home setting. How many neighborhoods do you think would want someone like my son living next door? He, like the others, would be the constant target to laughter and ridicule. They would not be free to take walks and ride their bikes like they are accustomed to doing because of the traffic and the fear of being harmed. The supervision is extremely important to these people and it is necessary for them. They have medical attention around the clock now. Who will be there for them in a group home?

It is hard for me to understand how a bunch of people who know nothing about my child or the other residents can make life shattering decisions for all of us.

Why don't you all just take a tour of the center and see what kind of people you want to force into "normal" neighborhoods. Maybe you and your neighbors would like to build one next door to you? Of course not.

So, I ask you as a citizen and a concerned parent to all handicapped adults and children, PLEASE REJECT BILL S-2053.

Maybe this bill should be brought to the attention of the public for their opinions and views on this matter. I'm sure the news coverage would prove me correct when I say only a handful of people would be willing to live next door to a group home.

The bill is unfair. It violates the rights of handicapped citizens and it is a terrible waste of the taxpayers money. Maybe someone should create a bill to upgrade the living conditions of these institutions instead of wasting all the space.

Yours truly,

Mr & Mrs Norman Landers

Testimony of

JUDITH K. LEWISON

before the

SUBCOMMITTEE ON HEALTH of the

U. S. SENATE Committee on FINANCE

on

S. 2053
"Community and Family Living Amendment of 1983

held on

August 13, 1984

Minneapolis, Minnesota

S. 2053 Summary Sheet Lewison

Summary Outline of Objections:

1. No one type of facility can serve ALL types of retardation disability.
2. Cost of care varies with different degrees of disability.
3. Overwhelming number of new group homes will be needed.
4. Difficulty in monitoring level of care in widely dispersed homes and foster homes.
5. Will eliminate the many good programs now in existence.
6. Each State should have the right to determine its own programs for serving the mentally retarded.

Testimony on S. 2053
"Community and Family Living Amendments of 1983
for Hearing Held on
August 13, 1984

I am opposed to S. 2053 because it is a bad bill. It is a bad bill because it is narrow, simplistic, and arbitrary in its objectives, and harsh, rigid, and dictatorial in its mandate. It is a bad bill because it is based on a series of erroneous assumptions. They are as follows:

1. It erroneously assumes that ALL mentally retarded individuals, regardless of degree of disability, can be adequately and appropriately served in only ONE type of facility, i.e., a group home housing no more than 8 (10) and no fewer than three. Who has made this momentous decision? This bill, on the prejudiced opinion of one man, will result in the total elimination, over a 10-year period, of all the good group homes now in existence that serve more than 10 people, -- programs that have been carefully developed over the past 10 or 15 years, by people who have worked in the field of mental retardation for many years; programs that have survived the diligent periodic scrutiny of the Accreditation Council and other monitoring bodies; have, in fact, received high ratings from these bodies. This bill will totally destroy them, in order to proceed on the unproven theory that units serving 5 or 6 people can be more economical and beneficial than those now existing.
2. This bill assumes that persons who are severely retarded and multiply handicapped can be served at the same cost as mildly and moderately retarded. Group homes have been established in many communities, over the past several years. They have come as a part of the broad continuum

of services, including day care, development achievement centers, sheltered workshops, and special classes in the public schools. They have served as the "next step" for institutionalized MRs, in their advancement toward greater independence. For many, it was in the institutional setting that they received the training necessary to achieve the degree of competence needed for placement in a community group home. Such homes are a necessary and proper setting for the moderately retarded. However, for the severely and profoundly retarded, and the medically fragile, the situation is different. These people need many specialized services, requiring a wider range of professional staffing. A physician should be on call at all times; full-time professional nursing care must be available; many kinds of therapy are needed: physical, occupational, and recreational. Moderately retarded individuals in community group homes can receive the necessary health care services from community sources. It becomes far more costly to do this in the case of those with the more profound handicaps.

3. This bill assumes that, when the institutions have closed their doors because of lack of funding, that all of the necessary small group homes will have appeared. Statistics show that this bill will affect approximately 117,000 now in 'insitutions', and another 50,000 in other facilities. At an average of 5 or 6 per home, as specified by this bill, 25,000 new group homes would be needed: an average of over 500 in each state. It assumes that each of these communities will have the necessary resources in terms of money, personnel, etc., to accomplish this. Laws will have to be passed forcing the delinquent communities to establish these homes,

and penalties assessed against those who do not. This again makes the Federal Government a "Big Daddy", so what has happened to the "New Federalism"?

4. This bill assumes that some of those too seriously handicapped to live in group homes can be placed in "subsidized family units", or "foster homes". Let me point out that, in the early years of "de-institutionalization, this was tried. Then came the horror stories; stories about fire hazards, personal injuries, poor health care, poor sanitation, inadequate housing lack of adequate programming, careless administration of medication, with no monitoring of side effects, and so on, and so on. Who will be able to monitor, on a daily basis, the care of these individuals? Will lawsuits arise as a result of such placements?

5. This bill assumes that all facilities now serving more than 10 people are "institutions", and that all 'institutions' are bad places, with poor care, no programming, and isolation of its residents. It also, with equal naivety, believes that all small units are "good".

6. This bill also assumes that all States have the same population density, the same problems, the same goals and standards, and the same resources, and can serve their retarded population in the same simple way, the way that this bill will mandate.

Mr. Chafee, one of the stated goals of this bill is to "integrate into the community" and "promote independent living skills" for all retarded persons. Very noble. But tell me, please, how do you "integrate into the community," and "promote independent living skills" for a person who cannot walk, cannot talk, cannot feed himself or control bodily functions, does not recognize his own peers, nor know his own name? Yes, Senator Chafee, there are such people in our institutions. Some are blind, some deaf. Some have deep-seated behavioral problems that have not responded to treatment. Are these the ones you would place in "some sort of extended community hospital facility", as someone has suggested? What would that cost per day? Or are these the ones who would be granted an extra 24-month grace period?

Senator Chafee, suppose we do go through with the procedure outlined in this bill, and over a 10-year period, as funding is withdrawn, the larger group homes disappear. Then, when there are no more institutions, these privately owned group homes began to close, one by one, because the costs, no longer buffered by State hospitals, begins to escalate; or because they cannot find, or cannot afford, the professional personnel they need. Where then will these retarded people go? We already know that many of those who were de-institutionalized in our earlier efforts have become "street people". They were placed into foster homes, or independent or semi-independent living arrangements; but the situations did not work out, and they were shunted from one place to another, until finally there was no place to go. We all have heard about the sub-standard housing unit that burns to the ground, ending the lives of retarded persons who have ultimately been placed there. Certainly, for each placement failure, there are several successes, but does that justify the final outcome for the less fortunate?

Let us "make haste slowly" in mandating the closing of the State "institutions" and the larger group homes. Let us find better ways to serve our mentally retarded, but let us not blindly make legislation that will cause a great deal of hardship and trauma, and eventual failure. Let us let S. 2053 die a blessed natural death.

Signed Judith L. Levison

Testimony given by:

Judith K. Lewison
Rt. 3, Box 26 A
Granite Falls, MN 56241

Qualifications:

- Parent
- Member of Minnesota ARC
- Residential Care Committee, ARC
- Governmental Affairs Committee, ARC
- Advisory Committee for Day Activity Center
- Secretary (formerly) to Board of Directors of Chippewa County Day Activity Center
- Officer and member of Parents' Group, Glacial Ridge Training Center

former positions held.

Aug 25, 1984

Dear Mr DeArment,

Regarding S.2053 - bill - "Community and Family Living Amendments of 1983". Wrote to Sen Chafee (12/21/83) stating my opposition to contents of above bill. Did not receive a reply.

Wrote to Sen. Proxmire - reply written to me, 2/6/84 - Also Sen Kasten, this letter dated Feb 10, 1984. If it is permitted would send you copies of their letters. Please let me know.

We have a son, David now twenty-one who has lived at Southern Wisconsin Center, Union Grove, Wi over fifteen years. All these years, the Center has been his home. He is on a small amount of medication and can be trained at present, to do simple work tasks. What training David has been able to achieve is a tribute to the people at So. Wi Center who care about the children of all ages there. They have cared.

There must be many So. Wi Centers in the country, I am strongly against the bill, it is wrong to short-change handicapped persons, to close state institutions to save money. For if any child, and every child as our laws profess, deserve the best, than why not allow the institutions who are giving the best do their job?

Sincerely

Phyllis Lorenzen
3862 E. Van Norman Ave
Cudahy, Wisconsin 53110

Holiday Florida
8/20/84

Mr DeArment

In regards to the bill S. 2053 which was presented by Senator John Chafee, of Rode Island on November 7, 1983 I am very much against this bill. My child and other children like her need the institutions facilities. They have a wonderful staff whenever we were up north we always stopped in. They really get good care. I have a sick husband and could not take care of my child. You could not find a better —

place for our children
that are helpless or
retarded. I think the
care is wonderful, I
think this would be very
wrong to support this
bill, I there comes a time
when a person or parent
cannot handle a child
then they must be placed
in an institution.
Children regardless of what
age must not be handled
like animals, They have
a good shelter, and also
plenty of food and a nice
place to sleep, They
also get educational
Therapy. When I was there
to see my daughter I
really saw severe
cases.

Mr. DeArment I wish you would consider this Bill as a serious matter. Our children need these institutions badly. No one likes to have their children in an institution but when children can't be handled at home then they must have a place to stay. And that is including the three big institutions in Wisconsin. I hope you think about this very seriously.

Your Truly
Mr. George Lucas

Burlington Wisconsin
August 28, 1984

Dear Sir:

I am writing concerning bill S.2053, "Community + Family Living Amendments of 1983."

My husband and I are against this bill.

We feel this would not be in our daughter's best interest and since she can't speak for herself we feel we must speak for her.

She is a 26 year old profoundly mentally retarded girl. She has severe scoliosis and rheumatoid arthritis. She has no speech. She is non ambulatory and requires total care.

There is a doctor, dentist, and nurse on call at all times. She also gets therapy to keep her hands as pliable as possible.

There are eight girls in her cottage. They are all severely handicapped. The aides and other personnel give them excellent care and attention. There are many other cottages like this.

We visit every week and so we can see for ourselves.

Group homes are fine for those who are able to care for themselves. We have several in Burlington.

It would be a shame to close Southern Wisconsin Center. Wherever these poor severely handicapped individuals would go they would have to have extra equipment and care and I think in the long run it would cost more.

Its a sad thing to be the parents of a child like this but we must go on and hope she will always get good and loving care.

Sincerely,
Mr + Mrs. Richard Lyke
Rt. 3, Box 822
Burlington, Wisc. 53105

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Aug. 27, 1984

I am again writing with regard to my opposition to BILL S.2053, "COMMUNITY & FAMILY LIVING AMENDMENTS of 1983". Several months ago, I mailed many letters to Chairmen, Directors, Senators and even President Reagan about this issue. I appreciated the response letter I received from two of them.

My boyfriend's sister, Heidi (Age 26) has known Southern Wisconsin Colony as "home" since she was 5 years old. She is quite severely retarded & the list of handicaps befallen her is almost too long to write. Over the years, much progress has been obtained from a trained, professional staff, medications and much therapy. I sincerely praise those special people in their ability caring to attempt to enable the less fortunate to have as decent of a life as possible. There is absolutely no way people like Heidi could ever exist humanely in just a small group home without the constant care they are so much in need of! Personally, I feel strongly against this bill and hope you will reconsider it. Please count me in with the hundreds of others who are also opposed to the closing of all state institutions for the retarded. Thank you.

Sincerely,

Cheri L. Mantie

CHERI L. MANTIE
2944 SOUTH 69TH STREET
MILWAUKEE, WI 53219

August 27, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

Dear Mr. DeArment:

We strongly oppose the bill S 2053, "Community & Family Living Amendments of 1983".

This bill will undo the last 6 years of many people's efforts. Our son, Ken, age 20, is classified as mildly retarded. He is aware of his differences and can not understand why. For the first 14 years Ken lived at home and attended the local schools until he began to mature. He could see the other children doing things he would like to but his body would not respond to his mind. In turn he became aggressive. We, as parents, then had to face the reality that our love was not enough for his future. He then went to Oconomowoc Developmental Training Center where he grew, learned and was happy. At age 18, being of legal age in Wisconsin, he was to leave there. So they started training for a group home, which as his parents we agreed and hoped for his future. The prospect of this was greater than his capabilities and Ken went catatonic. The hurt of the heart to see your son not recognize you or care was great. We brought him home and then searched for a facility where he could still grow and be content with himself.

Ken is now in Southern Wisconsin Center, a facility where they not only care for his body but his mind. The facility is clean, growing in their capabilities for advancement but the people care with their hearts as well as their hands. Ken is happy here and the joy in our hearts when we see him laughing and proud to be himself.

We are aware that our son has a long way to grow yet but without the help of this facility and these people Ken would become a stagnate human being having to be cared as an infant.

We strongly, with all of our power as parents of a special child, vote against this bill and will fight it for the best interest of Ken and the other children who are not capable of living in the community.

If the writer is so concerned about our special children, then let each state have guidelines for institutions to upgrade them to those in the state of Wisconsin.

One last word, not every child is able or can accept living in our world but will grown and become a more productive person in their world.

Sincerely,
Martin & Dorothy
Martin and Dorothy Mathison
Route 1, Box 66
Hillpoint, WI 53937

TESTIMONY TO THE
UNITED STATES SENATE COMMITTEE ON FINANCE
SUBCOMMITTEE ON HEALTH
IN SUPPORT OF
S.2053 COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

Regional Hearing August 13, 1984

Louise Whitbeck Fraser School, Minneapolis, Minnesota

Filed with:

Roderick A. DeArment, Esq.
Chief Counsel
Committee on Finance
SD-219 Dirksen Senate Office Building
Washington, D.C. 20510
August 9, 1984

Submitted by:

Elizabeth W. Bauer
Executive Director
Michigan Protection and Advocacy Service
for Developmentally Disabled Citizens, Inc.
313 South Washington Square
Lansing, Michigan 48933
(517) 487-1755

Principal Points of Elizabeth W. Bauer in SUPPORT of S. 2053

Medicaid represents a major funding program for citizens with disabilities. Over 50% of Medicaid funds now go to institutional care. Over 90% of physically and developmentally disabled people live in the community and require access to quality services.

Medicaid program administrators, program monitors and consumers agree that redirection of Medicaid funds to community and family based services will increase access to and quality of services. S.2053 with ARC/US recommended changes will accomplish this.

Community and family-based services are effective (disabled persons develop more and at faster rate) and efficient (costs for quality services in home and community are often less than costs for institutional services.

Institutional services endure because they have Federal financial participation, have become part of states' infrastructure, represent a familiar model to general public many of whom do not want to confront persons who are "different." Parental support for institutions may stem from desire to provide a lifetime placement (security) for their child and/or need to avoid revisiting painful placement decisions and/or need to maintain self-esteem which may be threatened by return of child to foster family or other community care setting.

Protection from harm and lifetime security are not guaranteed in institutional settings. All service settings require monitoring to assure quality over time. Community services are more likely to be observed by more people than are institutional services. People need to have alternative living arrangements available to meet their needs as they grow and develop.

Specialized services can be provided in any environment. The need for specialization does not justify segregation. Individualized plans of service incorporating elements from a mandated array of services must be developed with participation of all concerned persons including the recipient of service and where appropriate parents, guardians and advocates. S. 2053 with ARC/US recommended changes would provide a substantive mandate for planning.

S. 2053 with ARC/US recommended changes will provide states with incentives to develop home and community based services. It will reach persons previously unserved or underserved. Provisions for due process for parents, guardians and recipients of services will assure rights protection in the placement and service planning process. These are protections which only few persons - generally members of plaintiff classes in various civil actions - are now afforded.

Language must be added to S.2053 to assure maintenance of services currently covered in states' Medicaid plans as funds are redirected to community services. Specific timelines for implementation and performance expectations need to be added to assure states begin immediately to develop long range plans for family and community-based services and take the first steps toward realization of their objectives.

Testimony of Elizabeth W. Bauer in support of S.2053

The following comments are offered in support of S.2053. In making them, I draw on my experience as mother of four children two of whom have developmental disabilities. The oldest has epilepsy and our third child Ginny, has profound mental retardation with significant impairment in adaptive behavior. In Ginny's seventeen years, she has received intensive care and habilitative services at home, in a private residential facility (ICF/MR institution), in a specially trained foster family and in a small group home (her current residence). I also draw upon 25 years of experience of working with physically and developmentally disabled persons initially as a speech therapist and later as a special educator, special education program administrator, mental health executive and currently as Executive Director of the Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, Inc. the agency designated by the Governor of Michigan to implement the protection and advocacy system as provided for in the Developmental Disabilities Assistance and Bill of Rights Act. (42 U.S.C. Sec. 6001 et seq.).

In my adult life, I have lived in five states and have observed institutional and community-based services first hand in these and many others. I am convinced that with the necessary array of support services even the most severely impaired children may be served in their own home or a foster family setting and adults can remain in their home communities with out-of-family living arrangements tailored to their needs.

S.2053 would provide a funding mechanism to support development of an array of community and family-based alternatives to institutional services. It would also respond in part to the recommendations of the National Study Group on State Medicaid Strategies which was formed in 1982 to examine ways to control soaring costs of the Medicaid program and at the same time increase access to and quality of health care services to eligible persons.* As the Summary Report of the National Study group states, an increasing percentage of Medicaid funds goes to support institutional care. This expansion has come at the expense of other services such as in-home supports, personal care and improved coordination with other human resource programs. It has inhibited flexibility and contributed to inequities in the service delivery system which are unacceptable. One of the principle objectives of the study group's recommendations is to de-emphasize the use of institutional care for the elderly, disabled and mentally retarded and to develop a primary care system which would have added flexibility, capacity and resources to meet the special needs of multiply handicapped, physically and developmentally disabled individuals.

In the April 1984 report of the Inspector General, U.S. Department of Health and Human Services on "Transition of Developmentally Disabled Young Adults from School to Adult Services," it is noted that institutional costs for developmentally disabled clients constitute 40% of all Federal

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* Allen, Paul et. al., National Study Group on State Medicaid Strategies, "Restructuring Medicaid: An Agenda for Change" Summary Report, Center for the Study of Social Policy, Washington, D.C. 1984.

Developmental Disability services costs while serving only 6% of the developmentally disabled population with average state costs for ICF/MRs ranging from $24 to $167 per day. The Inspector General also noted that most respondents in his investigation felt that many of the developmentally disabled clients now placed in expensive institutional care could be served more appropriately in less costly and less restrictive settings and that a portion of the growing ICF/MR budget should be diverted to alternative levels of care.

Those who support the adoption of S.2053 with proposed revisions have chosen as a slogan "S.2053, It's Time, It's Right". Rarely has a legislative initiative to restructure a major funding resource enjoyed simultaneous support from so many recipients of the funded services and their families, administrators of the funding program and program monitors.

How did we come to create the institutional system which consumes such a disproportionate amount of our human services dollars? Historically, institutions were first developed in the mid-1800s to provide short-term education and training for persons with disabilities so that they could return to society as productive citizens. Later these institutions became the repository of persons who society wanted to care for but apart from the mainstream. Public support for institutional programs waned over time although the desire to separate people who were different from the mainstream endured. Overcrowded, understaffed conditions became the norm in the nation's institutional settings. Occasional bright spots appeared on the institutional horizon in the form of specialized training programs e.g. the Wayne County (MI) Training School Experiment in Self-Determination run by Samuel A. Kirk in 1935. But for the most part, the warehousing of society's devalued members went on unobserved for most of a century. Families who could not care for their disabled members at home did not have options other than institutionalization. Many made the recommended decision to part with their disabled child at or near birth. Others made that painful decision later when the lack of assistance and/or respite left them no alternative.

> "She is blind, deaf and profoundly retarded. Put her away and forget her." A noted pediatric neurologist spoke these words to my husband and me in March 1968.

We may ask why institutional care systems endure when we know today that programmatically superior alternatives can be provided in the community at reasonable costs and with greater integration of the disabled persons with society at large. Clearly the institutional system is a social structure in itself. Hundreds of thousands of people rely on it directly or indirectly for their livelihood. Federal reimbursement systems are integral to states' budgets. Since the 1970's when Medicaid funds were made available for ICF/MR construction, many states have upgraded their institutional settings and have incurred debts which they are still paying with Medicaid reimbursement. In fact, the President of the National Association of State Mental Retardation Directors stated in the western regional forum of the Administration on Developmental Disabilities, OHDS/HHS in

February 1984 that one reason for his organization's caution in supporting S.2053 as written was that many states were dependent upon Medicaid reimbursement to pay off bond issues let to renovate institutional facilities. It is incredible to me that professionals in the field of developmental disabilities who are aware of developments in habilitative programming and who have seen the difference in the rate of growth and development of an individual which can occur in a home setting can espouse a position which essentially requires that a group of people be held hostage in an institutional setting while a bond issue is retired.

Other forces which urge maintenance of institutions are members of the general public who would rather not have to confront people who are different from themselves and family members of those who live in institutional settings who have made the very difficult choice to separate from their loved one(s) for reasons they believed to be in the best interests of all at the time and who don't want to revisit those decision points. There is also an incredible need of parents and family members to believe that the choice they made was the right choice and that their child is receiving the best possible care in the only possible setting. I know, I am one of those parents.

> When we were told to put Ginny away, we investigated the public residential facilities in our state. They were not fit for any human to visit let alone live in. We sought private residential care at public expense and through manipulating the system obtained it . . . after five years.
>
> In the meantime, we trained dozens of people of all ages to work with our child

> in our home. Night and day for five years the door swung continually, the lights always burned. Our family members were the team leaders. Ginny's pre-school aged siblings became partners in management of her care and treatment. Many people volunteered their help. Other were paid.
>
> The last year she was home, we found a half-day training program which accepted her as she was. Even though it was 22 miles away, we made the round-trip twice daily to give her out-of-home program experience.
>
> In time, the drain on our personal, psychological and financial resources became too great. We could not go on. We placed Ginny in a private residential facility where a place for her "miraculously" opened up. We did not ask how. We put her away but we did not forget her. We monitored her care at all hours of night and day and days of the week. We justified her separation from the family on the basis that ONLY in such a specialized setting could her needs be met.

In the years Ginny was learning to suck and swallow, to sit, stand and walk, to recognize shapes and colors and follow simple directions, a revolution was taking place outside institution walls. Parents of children with disabilities were going to the courts and their legislatures to get special education services for all children. Lack of educational opportunities had been a major reason for institutionalizing children in the past. People began looking more closely at the institutional system and were horrified at conditions they encountered. Lawsuits to obtain freedom from harm, rights to treatment and placement in less restrictive alternatives were filed in many states and community-based service delivery models received more attention. With special education services available to all children, more children remained in their own families. With the courts telling states they had to close their institutional settings, more people returned to the community with an appropriate array of support services. Some states such as Michigan saw the value to the people concerned and the state as a whole in moving to a community and family-based service delivery system and took steps in that direction on their own initiative as well as in response to statutory change and court orders. The more individuals who moved successfully to the community, the more it appeared possible for people with disabilities to remain in or return to their own homes or home communities.

An ancient proverb says that the longest journey must begin with the first step. Nowhere is that more apparent than in the progressive modifications of the federal court order in the civil action brought by the Michigan Association for Retarded Citizens against the Michigan Department of Mental Health. The initial consent agreement in 1979 called for reduction of the population of Plymouth Center for Human Development to 100 persons from the more than 800 who had lived there when the lawsuit was filed. As time went on, individuals moved back to their own homes, to foster families, small group homes, semi-independent apartments and other community-based living arrangements. Their success in reintegrating themselves in the community made it appear more possible for those remaining in the institution to do likewise. Ultimately the order was modified so that everyone would leave and the Plymouth Center would close.

From an initial group of 100 "who could not make the transition to the community," there are but a handful who are not yet there. Most agree if we had the financial resources to pay for the specialized services they require, they could be.

> When Ginny was 12 years old, it became clear that her cloistered, segregated environment was stultifying rather than stimulating her development. She had gained the basic skills they set out to teach her and she needed socialization experiences and challenges she could not get in an institutional setting no matter how fine the habilitation services.
>
> We accepted this on an intellectual basis and began vigorously to pursue transfer for her to Michigan. We found the perfect foster family care setting through the Macomb-Oakland Regional Center of the Michigan Department of Mental Health and jumped through all the required hoops to gain her admission to services. There are two points to be made here: one has to do with the CHOICE of foster family care and the second with our RESPONSE as Ginny's natural family to that placement.
>
> The choice of foster family care was in a large part determined by the availability of services and funding mechanisms. As her natural family, we were not eligible for any support if she were cared for in our home and we could not afford the assistance we would need beyond special education services. However, specially trained foster families under contract to the Michigan Department of Mental Health through the Macomb-Oakland Regional Center were not only paid for their services, they had access to medical/nursing/psychological support services and other therapeutic assistance. A case manager was available to broker for generic services as needed. It was clear that her needs and our needs were best met by the foster family placement.
>
> My response to this placement when it actually occurred was both painful and enlightening. As I drove Ginny to her new family, I experienced an overwhelming sadness which I later identified with the help of a therapist

> later identified with the help of a therapist as anxiety caused in part by the separation from her surrogate parents in the institutional setting and in part from the blow to my self-esteem resulting from the knowledge that another ordinary family was going to do what I with all my education and training in the field could not do.
>
> I worked through this significant emotional event and came to develop a warm relationship with Ginny's foster family. I regained my sense of self-esteem and went forward in my own life's work. Subsequently, I have worked with many, many people who were experiencing similar discomfort around a change in placement of their family member. Through sharing of hopes and fears, joys and sorrows, we have found a new peace in ourselves and promise in the new environment of our loved ones.

Sponsors of S.2053 have heard from many parents who oppose the provisions of the bill which would encourage the phase-down or phase-out of institutional settings. Some have stated that community and family-based services are still in the experimental stage, that they cannot adequately serve persons with severe and profound mental retardation. They justify the need for segregated facilities on the grounds that only there can their family members receive the specialized services they require. They argue that the security of life-long placement in a single place which is regularly monitored is preferable to placement in alternative settings. I submit that these are very real concerns. But they are concerns without foundation. There is no security that an institution will stand forever. In Michigan, in the last two years, four have been closed. Specialized services depend upon the availability of qualified educators, therapists, medical and allied health personnel. These and other specialists can go to work in community and family-based settings just as easily as they can go to work in an institution. Monitoring annually or every two years by licensing, certification and accrediting bodies does not assure a safe place with quality care. As Executive Director of the Michigan Protection and Advocacy Service, I visit institutions, community homes and foster family care settings on a regular basis. By far the worst abuses of individuals and violations of standards of quality of care have been found in accredited institutions. On a single visit to an accredited institution, I observed among other things, an absence of staff interaction with residents, an absence of personal care items (toothbrushes, hairbrushes, toilet tissue, soap, towels), 32 men wearing identical jumpsuits one-size-fits-all standing in a dirt courtyard surrounded by a six-foot chain link fence while the four staff sat in the only chairs and cued residents to tell us how great the staff were. We found a woman tied to a toilet with a bedsheet--left there so long she had fallen asleep. She was distrubed only by the nurse who woke her to administer medication and then left her unattended! Poor quality of care can exist anywhere. It is more likely to obtain when out of sight and mind of concerned others. Community-based care settings are monitored not only by program personnel but by neighbors who have a vested interest in maintaining a well-run program in their midst.

People who are out and about, who are seen and heard COUNT. Reintegrating persons with disabilities into the mainstream of society requires valuing those persons as individuals. S.2053 in restructuring the reimbursement priorities of Medicaid is indeed restructuring our value system as it regards our fellow citizens. In a statement entitled The Community Imperative, the Center on Human Policy at Syracuse University wrote in 1979,

> ". . . In fulfillment of fundamental human rights and In securing optimum developmental opportunities, All people, regardless of the severity of their disabilities, are entitled to community living."

That same year in his Memorandum, Order and Decree in the Plymouth Center case, Judge Charles W. Joiner, U.S. District Court, Eastern District of Michigan wrote,

> ". . . A commitment to the development of a comprehensive system of appropriate less restrictive habilitation, training and support services for each member of the plaintiff class. All mentally retarded individuals can and should live in the more normalized environment of the community and do not require institutionalization, given the development of necessary habilitation and support services in the community."

Based on the experiences of placing members of the plaintiff class in appropriate community settings in addition to the success of community and family-based services developed on its own initiative, the Michigan Department of Mental Health has made a commitment to halt admissions to institutional care to the extent possible and re-direct those persons requiring out-of-home care to community services. The effort has been so successful that it is rare for a child to be placed in an institutional setting and even those that are referred by Social Services for placement in nursing homes must first be referred to the Department of Mental Health to ascertain if they can be appropriately served in a community setting. The institutional population in the state has been reduced from over 12,000 only a decade ago to less than 2,500. The number of persons remaining in specialized nursing homes is just a few hundred. In the next years, we hope they too will join us in community lving and that none will be sent to take their places. In fact, James J. Blanchard, Governor of Michigan in his 1984 State of the State message wrote,

> "Efforts must also continue to provide services to children requiring out-of-home placement in the most appropriate and least restrictive manner which supports their growth and development. I am instructing the Human Services Cabinet to coordinate these efforts so that we can set a goal that by the end of 1986 no developmentally disabled child will be institutionalized."

Within Michigan community living has been demonstrated as programmatically effective for most people. It is also cost effective. Institutional settings in Michigan range in cost from $114 to $197 per day. Small group homes for severely impaired persons with specialized care needs range from $91 to $132 per day. Small group homes for persons who require less assistance in meeting their personal needs are about half this cost. Foster family care settings are even less costly.

In 1984, Michigan made a major change in public policy by passing the Family Support Subsidy Bill which will provide a monthly stipend in the amount similar to the Supplemental Security Income payment to natural families of persons who are severely multiply impaired, severely mentally impaired and severely autistic impaired. This payment which will not be treated as income to the family will permit families to obtain human and material resources which will enable them to maintain their disabled family member at home. It is probably not enough nor does it serve all the people who might need such assistance but it is a beginning, a first step toward building a partnership with the natural families who for so long have had to separate themselves from their family member in order to obtain necessary services.

Another step in the long journey to a community and family based service system are the Community Care Waivers currently obtainable through the Health Care Finance Administration. While not every state has utilized this provision, those that have are adding to the information available on the merits of community care.

As we look at the provisions of S.2053 and the proposed changes submitted by ARC/US in April 1984, it is clear that the primary purpose of the legislation is to promote a range of habilitative services in the community and to encourage the return of persons now living apart in institutions by providing for their needs in a community setting. The range of services to persons with physical and developmental disabilities which would be reimbursable under the bill is exciting. It is important to assure that persons already living in the community benefit from this expanded program at the same time as those who are returning do. We need to assess what full implementation of this program will cost in total Medicaid dollars. It is my belief that over time it will be cost effective. It is not a bricks and morter program. It reimburses services not construction costs. We know from experience in special education that early intervention prevents or at least ameliorates disability conditions. The more we can help a person toward independence, the less we will have to spend for dependent care.

> When I walk through institutions, I see many individuals who cannot walk or even sit or roll over. Their joints are frozen and their muscles have atrophied from long years of disuse. Upgraded services of recent years cannot correct the damage done by years of lying in a crib. Many of these people were born with joints, muscles and sensory apparatus more intact than were Ginny's. It grieves me that we have done them such a dis-service. Ginny walks today because so many children and adults worked so faithfully and long to stimulate her senses and exercise her limbs. She has no debilitating contractures but she might have had if she had been placed in a crib and ignored in her silence.

Recent comparisons of functioning levels and rates of development between persons in institutions matched with persons in community care have shown that those residing in the community make greater developmental gains at increased rates of development. It appears too that the greater the individual's needs, the smaller the setting should be. (Keith and Ferdinand, 1984) (Conroy and Bradley, 1984)

> In 1981, Ginny moved to a small group home in a regular neighborhood. She and four other teen-agers attend school in a 230-day program due to their particular needs. The home staff (three each on day and afternoon shifts and one on the midnight shift) work with them to develop their social and personal care skills. Sign language and other communication skills are worked on daily.
>
> Ginny's rate of development has accelerated in this environment. At 17 she's encouraged to do

> things for herself to the extent possible and she continually surpasses our expectations of what is possible. While we celebrate her rate of growth and development, it pales in comparison to the change experienced by her roommate Sally (not her real name). Sally, aged 16, came to the house from a large institution. Through my work I had known her since she was eleven and through documents, I had known something of her life before age 11. When she arrived, she displayed classic "institutional" behaviors. She tore her clothes off at the slightest provocation, ruminated, belched, spit, screamed and made ugly noises, stole food at the table and was aggressive toward her housemates. The fact that she was a Hepatitis B carrier made it even more difficult for people to want to be near her.
>
> However, staff in the home setting with professional assistance developed interventions and training programs to teach her more acceptable behaviors. Most of all they accepted her as a teen-ager who like all teens wanted to be a member of the group. They reached out to her as a person and taught her new behaviors directly and incidentally. Each week I saw dramatic improvements. Within six months, there was a whole new person greeting me at the door. Today when I arrive, I am met by a smiling young woman who is dressed attractively and who prides herself on her appearance especially her long blond hair. I wish I had a videotape record of her metamorphosis. It would be a compelling documentary.

Could Sally have learned her new skills in the institution? Possibly, but it would have been difficult. It's hard to learn to style your hair when you don't have dryers, mirrors, combs available. It's hard to stay clean when you bathe only three times a week. It's hard to learn to dress attractively when your clothes are limited in number and not necessarily coordinated or the latest style. It's hard to learn to cook when the central kitchen is a half mile from your building. There's no need to set the table when food is served on a disposable sectioned tray. When you have to shout or act-out to get attention, quiet, modest behavior is not likely to occur. While costs should not be the measure of a quality service, it is interesting to note that the per-diem cost of care in Sally's institutional setting has been as high as $229 per day while the cost of care in her present home is less than $100.00.

Sally's story has been repeated over and over as individuals have left institutions and specialized nursing homes in Michigan to return to their own or foster families, to move to small group homes, apartments or other community living arrangements. One of the outcomes of having to move people from institutions on court-ordered schedules is that we have learned that people do not have to be "ready" to move successfully. The myth that people should know all there is to know about community living before leaving the institution has been debunked. Rather, it is the community which needs to get ready for their return by establishing the necessary support services and extending a hand in welcome. One of the strengths of S.2053 is the requirement for an individualized service plan which is developed cooperatively by staff of the institution from which a person is leaving and professionals in the community, the recipient of service and parents, guardians and advocates as appropriate.

S.2053 in requiring a phase-out of Medicaid funding to institutional settings over a 10-15 year timeline creates a condition wherein it is in the interests of states and their citizens to develop community and family-based alternatives. Changes to the bill recommended by ARC/US in April 1984 would require an 85 percent rather than 100 percent withdrawal of funds and assure that adjustment for inflation is made so that states will have 15 percent in real dollars available for institutional care at the end of the stipulated time frame. Proponents of the modification hope this will enable states to maintain levels of care in institutions still in place at the end of the phase-down period. It may also give time for people in states where community and family-based services are less developed to become acquainted with successful models of service first hand and develop their own commitment to them.

It is important to remember that the funding resources which would flow to the community if S.2053 becomes law would also provide for services to people already in the community not just those leaving institutions. ARC/US has recommended eliminating the provision in S.2053 which provides a 5 percent higher Federal match for home and community services to persons who were institutionalized for the first five years following their return to the community. Instead they propose addition of a provision which would reduce the Federal matching rate for institutional services while maintaining the Federal matching rate for home and community-based services. This change would produce a more equitable support for persons who have not been institutionalized while maintaining the incentive to states to move to a community-based service model.

To avoid confusion in definition of eligible populations for benefits of S.2053 vis a vis eligible populations for other Federal benefits, ARC/US and we support amendment of the definition of the eligible population to conform with the definition of disability in Section 223 of the Social Security Act. We also support the proposed amendment to permit children who are mentally ill and who are under the age of 21 when S.2053 is passed to maintain their eligibility for services into their adult years.

In general, we support the concept of S.2053 and the recommended changes proposed by ARC/US in April 1984. In addition to those mentioned above, we want to single out for emphasis the provisions for protecting existing services as people become eligible for services under S.2053. Language should also be added to prohibit states from suspending, reducing, discontinuing or terminating the medical assistance provided under their state plan because of any financial constraints created by the reductions called for in S.2053. This does not necessarily mean that the states must maintain the same total dollars for services to disabled people.

We support the proposal to require states to include an array of community and family support services in their plan. ARC/US has proposed an exhaustive list and no doubt there will be others mentioned in the course of these hearings. Experience has shown that unless services are specified and mandated they may not be forthcoming.

Finally, we urge inclusion of the proposed timelines for implementation particularly the one which would require states to provide some family home and community services in the first year following enactment of S.2053. As mentioned earlier, the longest journey must always begin with the first step. By developing one community home or providing services to one person in his own home it will appear more possible to do the same for others.

S.2053 when passed will create an opportunity to alleviate fiscal and programmatic pressures on the Federal-State Medicaid program, to increase access to and quality of needed health care services and to promote community and family-based services according to a long-range plan and with sufficient resources to accomplish its objectives.

Resources

S.2053 Community and Family Living Amendments of 1983

ARC/US Recommended Changes to S.2053 "Community and Family Living Amendments of 1983", April 17, 1984.

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Bradley, Valerie J. and Conroy, James W., *Fourth Year Summary Report of the Pennhurst Longitudinal Study*, Philadelphia: Temple University Developmental Disabilities Center, 1984.

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STATE OF MINNESOTA
DEPARTMENT OF HUMAN SERVICES
CENTENNIAL OFFICE BUILDING
ST. PAUL, MINNESOTA 55155

August 31, 1984

Roderick A. DeArment
Chief Counsel
Committee on Finance
Washington, D.C. 20510

Dear Mr. De Arment:

Enclosed is a position statement by the Minnesota Department of Human Services on the "Community and Family Living Amendments" (S. 2053).

We respectfully request inclusion of this statement in the printed record of the hearing.

Sincerely,

LEONARD W. LEVINE
Commissioner

Enclosure

AN EQUAL OPPORTUNITY EMPLOYER

[illegible]
(8-84)

STATEMENT ON SENATE BILL 2053

"Community and Family Living Amendments of 1983:

Submitted by

Leonard W. Levine, Commissioner
Minnesota Department of Human Services
Fourth Floor Centennial Office Bldg.
St. Paul, Minnesota 55155

Summary of Position

The Minnesota Department of Human Services is unequivocally committed to the policy goal of social and physical intergration of persons with mental retardation into the community and to the development of service options that allow them to live their lives with dignity and independence.

However, the Minnesota Department of Human Services (DHS) does not support the "Community Living Amendments of 1983" (S. 2053) in its present form. Specifically:

- We support the expansion of community services outlined in the bill. Additional language should be added detailing specific community services available under the program.

- The proposed definition of "developmental disabilities" is more encompassing than the current Minnesota definition and will pose administrative difficulties. The definition established by the Minnesota Legislature is better. Moreover, the obvious increase in demand for services that will accompany this broadened definition needs additional fiscal analysis.

o The provisions in the amendments for the staged reduction of federal financial participation in the costs of care in larger facilities would pose serious problems for Minnesota. There are 6866 Minnesotans living in IGF/MRS. Less than 30 percent of these persons live in facilities serving fewer than 16 residents. While the State is actively committed to the development of small community facilities, the phase-out provisions gloss over the complexity of the process of defining change. The State of Minnesota has seven institutions serving persons with mental retardation. The proposed reduction of administrative support would unnecessarily restrict the state's flexibility in planning a future course for these programs.

Senate Bill 2053 embodies many concepts that describe Minnesota's current program initiatives in services to persons with mental retardation:

-support of family integrity by providing services close to family and friends;

-recognition that life in the community not only enriches the lives of all of us, butalso provides a potent habilitative environment for persons with severe disabilities;

-recognition that careful service planning and assurance of quality in the service delivery system are critical;

-protection of the rights and benefits of current employees; and,

-that meaningful vocational training and employment opportunities are essential to the personal independence of persons with severe disabilities..

In these areas, Minnesota supports strongly the public policy implicit in the amendments. The concepts embodied in S. 2053 represent sound national policy and an affirmation of Minnesota's own policy initiatives.

The mechanics of the current Bill present Minnesota with some severe, and likely insurmountable implementation problems.

The definition of "developmental disabilities" poses problems. Senate Bill 2053 proposes a definition of "developmental disabilities" that is too encompassing. Currently, Minnesota statutes set forth clear criteria for determining the presence of mental retardation or mental illness. The Minnesota Legislature appropriates resources for the provision of services based on a clear, historical understanding of the nature of the services provided and the needs of Minnesotans who receive the services.

The "Community and Family Living Amendments of 1983" proposed definition is less well articulated than that which has been established by the Minnesota Legislature. The definition may be unadministrable. In mandating the proposed definition, the Congress will create conflicts and confusion between Federal directives and Minnesota's established policy goals.

As federal program policy has shifted rapidly away from the provision of care in large, segregated facilities and toward small, community-intergrated, habilitation-oriented services, federal funding and regulatory policies have been slow to respond. The result has been a clear federal emphasis on community-based service delivery with funding and regulatory policy continuing to provide incentives for providing services in large care facilities. Minnesota's efforts to repond to this change in program policy in the face of federal funding and regulatory mechanisms that encouraged the development of large facilities and discouraged the development of small, community-based facilities has been labored and has resulted in costly and protracted litigation. Minnesota's experience has been similar to that of some other states.

Recently, the advent of the medicaid home and community-based services waiver has been a first step towards aligning federal program and funding policies, and has stimulated a significant amount of activity related to the development of small, community-based services. The medicaid waiver deserves continued Congressional support and study. Moreover, The Congress should exercise its oversight authority and make sure the waiver provisions of Section 2176 are properly implemented. We are beginning the waivered services program initiative in an environment that is the product of following the direction of federal funding policies in the not too distant past. The existing service system is one in which only 636 Minnesotans with mental retardation live in community-based ICF/MRS of six or less; 2,198 live in community-based ICF/MRS of 7-16; 1,527 live in community-based ICF/MRS of 17-99; and 841 live in community-based ICF/MRS of 100 or more. Minnesota now has the highest per capita rate of placement in ICF/MRS 16 or more residents of any state in the nation---110 per 100,000 population. By comparison Louisiana is a close second, and West Virginia has the lowest rate---9 per 100,000 population. There are at least three conclusions to draw from these data:

-measure to implement S.B. 2053 must be vastly different from state to state to allow for the considerable differences that exist among the states;

-Minnesota and some other states will be faced with large administrative tasks, and,

-the proposed sanctions for not complying with the provisions of S.B. 2053 would be particularly severe for Minnesota and the more than 4,500 individuals who will be affected.

Minnesota is committed to changing our service configuration to achieve a greater variety of small community-based service settings. However, the proposed planning and enforcement mechanisms, and the associated sanctions of S.B. 2053 would be disruptive. Congress must consider the damage that the sanctions and enforecement mechanisms proposed in S.B. 2053 will have on the long-run evolution of service systems in state like Minnesota. Congress should consider alternatives which allow for management flexibility for states and tie federal financial incentives to individually determined state goals for program size reduction.

In summary, I would like to reiterate Minnesota's strong and demonstrated support for the program concepts and the expansion of community-based services embodied in the "Community and Family Living Amendments of 1983". Other provisions in the amendments which impose financial sanctions and restrict the administrative perogratives of the states should be changed. In Minnesota, we have a long tradition of providing humane and effective services to persons with severe disabilities. It is our intention to continue that tradition even more aggressively into the future.

TESTIMONY

SUPPORTING S. 2053
THE COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

Presented by:

Minnesota Governor's Planning Council
on Developmental Disabilities

Before the:

Senate Finance Committee on Health
United States Senate
Minneapolis, Minnesota

August 13, 1984

The Minnesota Governor's Planning Council on Developmental Disabilities supports S. 2053, The Community and Family Living Amendments of 1983, including the changes and amendments recommended by the Association for Retarded Citizens - United States. In July of 1984, the Council adopted the following resolution:

S. 2053 COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

This bill provides expanded Medicaid coverage for family and community-based services for mentally retarded and other severely disabled persons. Its primary focus is severely disabled recipients of Supplemental Security Income (SSI). Federal Medicaid funds for institutional care would be phased out and redirected to more appropriate cost-effective home and community services, and this bill establishes new monitoring provisions and other protections.

WHEREAS: The Community and Family Living Amendments of 1983 mandates long-range, systematic planning for community-based services systems while providing for an appropriate shift in Medicaid funding to support such planning; and

WHEREAS: The Community and Family Living Amendments of 1983 supports the idea that the place for people to build their futures is in the community; and

WHEREAS: The Community and Family Living Amendments of 1983 is a response to the needs of individuals by supporting an array of services which facilitate community integration and quality of services; and

WHEREAS: The Community and Family Living Amendments of 1983 establishes new monitoring provisions and other protections for people with disabilities living in the community.

THEREFORE BE IT RESOLVED: The Governor's Planning Council on Developmental Disabilities supports the bill with its recommended changes, proposed by the National Association for Retarded Citizens, and expanded eligibility requirements to include persons with mental illness and other disabilities.

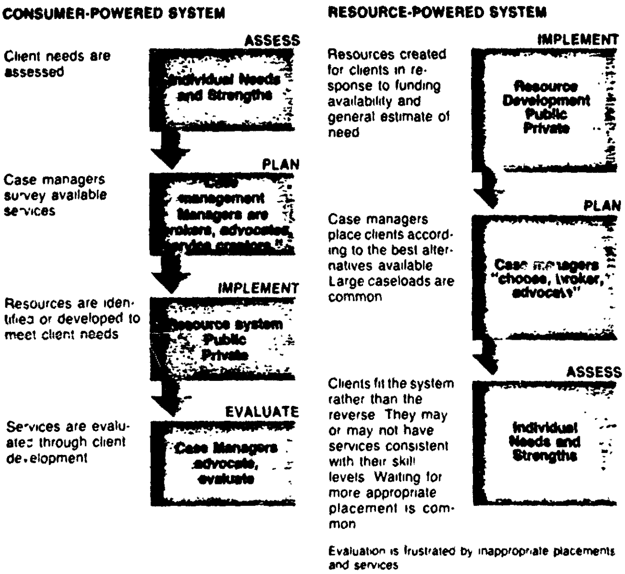
The introduction of S. 2053 provides an opportunity to examine several issues surrounding services especially residential services for persons with developmental disabilities.

The Minnesota Governor's Planning Council on Developmental Disabilities welcomes this opportunity to discuss the issues and offer observations about the current service system in Minnesota.

1. <u>Consumer-Driven System</u>

   Overreliance on construction of facilities or the maintenance of an already existing service may inadvertantly direct public resources to meet the needs of a system (bricks and mortar) rather than the needs of people. To be responsive to an ever-changing profile of clients, the service system itself must adapt and be capable of change. ICF-MR facilities should be viewed as one type of service within a broader array of programs and services available to people with developmental disabilities. Those services should remain flexible and promote, wherever possible, movement into more independent (usually less costly) settings. To achieve those ends, funding mechanisms should accommodate people; not programs. (Policy Analysis Series Paper #15, March 14, 1983.)

   In Minnesota, individuals are made to fit services rather than services designed for individuals. The difference between "consumer powered" and "resource or provider-driven" system is illustrated as follows:



Client needs are assessed

Case managers survey available services

Resources are identified or developed to meet client needs

Services are evaluated through client development

Resources created for clients in response to funding availability and general estimate of need

Case managers place clients according to the best alternatives available Large caseloads are common

Clients fit the system rather than the reverse They may or may not have services consistent with their skill levels Waiting for more appropriate placement is common

Evaluation is frustrated by inappropriate placements and services

S. 2053 recognizes and supports the empowerment of consumers and places high priority on families. This is the first time that Congress has recognized the family and small community settings as the option of first choice.

2. Meeting Demands for Service

Much of the demand for community placements in Minnesota could be met by existing ICF-MRs if appropriate alternative services for many current ICF-MR residents were developed and adequately funded. For many people, ICF-MR services may be the most appropriate service model; for others, that level of service may represent only one step in a process of growth and change. Quality Assurance Review (QAR) data suggest that as many as 200 people now living in group homes in Minnesota are ready to move into semi-independent living settings; other estimates indicate that, with varying levels of supervision, as many as 1,000 people could be placed into foster care or semi-independent living programs (Copeland and Iversen, 1981). S. 2053 allows flexibility in the service system to meet needs in a range of alternative living arrangements.

3. Size of Community Facilities

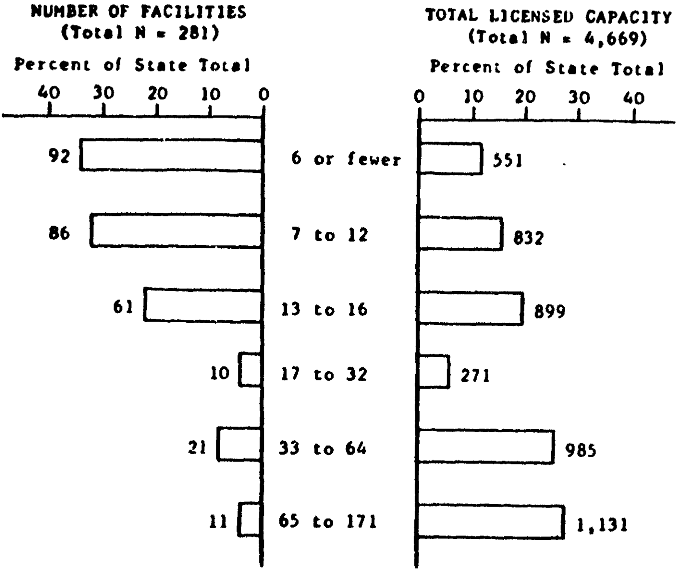
Size of facilities remains an issue. Current studies by the Minnesota Developmental Disabilities Council (Policy Papers #4, #15, #19) indicate that the smallest facilities are not the least costly. Several mitigating factors should be considered, however. Most of the smallest ICF-MRs are relatively new facilities. Inflation and the recent increases in the costs of construction and financing may account for much of those cost differences. Additionally, people now being placed into community facilities are more likely to have lower levels of functioning and/or physical handicaps than people placed several years ago in older facilities. Higher resident dependency levels suggest higher staff-resident ratios; hence, increased costs. Finally, the literature suggests that when all factors are considered, the psychosocial and developmental needs of individual residents are more likely to be met in small, homelike residential programs, rather than in larger facilities. Such factors include:

- individualized attention (Baroff, 1980)
- resident oriented care practices (Balla, 1976; Baroff, 1980; King, Raynes & Tizard, 1971; McCormick; Balla & Zigler, 1975)
- absences of security features, existence of personal effects, privacy in bathroom and bathroom areas (Balla, 1976; Baroff, 1980)
- community exposure, social interaction (Crawford, 1979; Baroff, 1980)
- experienced, trained direct care staff (Bellinger & Shope, 1978; Baroff, 1980).

4. Larger Community Facilities

The appropriateness of larger community ICF-MRs also needs to be addressed. In 1980, the ten largest facilities in Minnesota accounted for nearly one-quarter of the total community ICF-MR bed capacity. Some facilities exceed the size of state hospital programs. In 1980, nearly half (49%) of the people in community-based ICF-MRs lived in "group homes" with more than 32 residences. The figure below graphically depicts the size range of Minnesota facilities.

FACILITY SIZE[a]



[a] Developmental Disabilities Program, *Policy Analysis Series Paper No. 19: An Update to Policy Analysis Series No. 4 and 15: Cost Function Analysis of Minnesota Intermediate Care Facilities for Mentally Retarded (ICF-MR) Per Diems: 1981* (St. Paul, MN: Developmental Disabilities Program, State Planning Agency, August 14, 1983).

5. Less Costly Alternatives

Community ICF-MR programs are not cheap. In fact, the costs of a community placement for a former state hospital resident may approach those of the state hospital system--when costs of day programming and support services are included. This is most true for children. Residential and day programs for children are relatively more expensive than adult programs. Consideration should be given to developing in-home support services and expanding family subsidies for children. Not only are these programs more cost-efficient, but they may help to forestall or alleviate the need for placements into costly institutional and ICF-MR settings.

We are extremely pleased with the concept of the Title XIX Home and Community Based Waiver. While the provision of these services under the Medicaid Waiver is important in the development of less costly alternatives, only a limited number of people can be served by specific types of services such as supported living arrangements and in-home supports. One useful service not covered by the waiver in Minnesota is Semi-Independent Living Services (SILS). The provision of SILS involves placement of adults in small units (2-4 people) where they are supervised by a licensed agency and provided with services based on need, including training in cooking, shopping, hygiene and using public transportation. The purpose of SILS is to train for independence or to maintain individuals in semi-independence. SILS room and board are paid from the following sources: Supplemental Security Income (SSI), Minnesota Supplemental Aid (MSA), Social Security

Section 8 (HUD), General Assistance (GA), wages, food stamps, and combinations of these. As of December 30, 1983, there were 67 licensed SILS agencies with a total capacity of 1,290 persons in Minnesota. Shifting use of Medicaid dollars as proposed in S. 2053 would permit expansion of services like those available under the waiver and the development of other services such as SILS which allow for increased independence of persons who are mentally retarded. Further, they are compatible with cost considerations and consistent with policy statements which promote normalization and least restrictive living environments.

6. Support Services

The further development of ICF-MR programs, as well as other community-based residential care programs, cannot proceed without also considering the availability and appropriateness of community support services. There are at least two major areas of concern: (1) the availability of day programs and (2) adequate case management services.

A. Adequate and Appropriate Day Programs

The ultimate success of residential care services is highly dependent upon the availability of appropriate day programs--programs committed and geared toward client growth and development in self-help skills, academics, vocational skills, and meaningful employment. Current opportunities are limited. Data indicate that many potential clients are waiting to participate in developmental achievement center programs. At the same time, current DAC participants are ready to move into sheltered workshops but are unable to make those transitions because there are no vacancies (Policy Analysis Paper No. 8, 1982). Future development of community residential programs must be closely tied to the availability of quality day programs which are capable of meeting the individual needs of residents.

B. Case Management

Finally, the success of community programs is also dependent upon an adequate supply of case management services. In a system of care which is becoming more and more decentralized, it is imperative to have in place and operating a workable case management system (i.e., reasonable caseloads) which can help ensure that appropriate programs and services are available, that necessary services are provided, and that quality of programs is maintained. Few places in Minnesota have adequate case management services.

7. Target Population

We fully support the definition of developmental disability in S. 2053. We are concerned that two groups be considered for inclusion: emotionally disturbed children and mentally ill persons. If S. 2053 cannot address these groups, then we urge Congress to consider the needs of these persons in the near future.

Conclusion

A belief in human dignity, that each person is unique and capable of development unlies protection of the basic rights of individuals. While the majority of people with disabilities live independently, some people need either temporary or long term help from society. S. 2053 as proposed provides an excellent opportunity for society to explore more cost effective, less restrictive methods of care for persons with developmental disabilities. The attached document "Position Statement on Service Provision to Developmentally Disabled People" further defines our Council's position.

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Minnesota Governor's Planning Council on Developmental Disabilities
DEVELOPMENTAL DISABILITIES PLANNING OFFICE OF THE STATE PLANNING AGENCY
200 CAPITOL SQUARE BLDG. • 550 CEDAR STREET • ST. PAUL, MN 55101 • 612-296-4018

POSITION STATEMENT ON SERVICE PROVISION TO DEVELOPMENTALLY DISABLED PEOPLE - 1982

Changing social and political priorities require a social service system to frequently restate its fundamental ideology. The ideology clarifies the purpose and importance of the goals and objectives. A community appraisal of the ideology will clarify whether the commitment to these ideals remains or if other priorities have been established.

The ideology of the Minnesota Governor's Planning Council on Developmental Disabilities includes the following:

1. INDIVIDUAL VALUE: Our nation has proclaimed that all persons have basic rights including those to life, liberty, and the pursuit of happiness. This commitment is based on political, philosophical, and theological beliefs that each person is fundamentally equal. Over the last two centuries, disenfranchised groups have become recognized as contributing citizens. The Governor's Planning Council on Developmental Disabilities is committed to the recognition of value of individuals who are developmentally disabled. Every person has the right to equal respect, dignity, rights and responsibilities.

2. DEVELOPMENTAL MODEL: Every person is capable of growth and development regardless of the severity of his or her handicapping conditon. An individual continues to grow as long as habilitative opportunities exist and are not limited to specific chronological ages.

3. THE NORMALIZATION PRINCIPLE: Individuals, by definition, are unique from one another. These differences can be reduced or intensified depending upon the education and experiences of both individuals and society. The normalization principle draws from the belief that the individual's ability to contribute to society is directly related to his or her opportunities to participate in the society.

4. CONSUMER PARTICIPATION: Maximum consumer involvement in determining needs and services will increase the effectiveness of the services. The consumer knows his/her own needs best, and establishing accountability of service delivery systems with consumers and their representatives can lead to higher quality services.

Statement of Objectives

The basic guidelines for a service system are the formal goals, those which "are the designated, chartered, and manifest intents of an organization.

These goals represent what the organization is designed to accomplish, its reason for being, and its objectives for society and for the population or clientele it serves" (Miringoff, 1980). Clearly stated objectives communicate to the clients served, the service staff, and the community at large the direction and purpose of the work undertaken. They provide a critical tool for evaluating the daily activities to the fundamental ideology.

The following objectives represent the proposed direction of the Governor's Planning Council on Developmental Disabilities:

1. <u>To obtain or provide services at local levels so that people who are or become developmentally disabled can remain in or return to their communities</u>.

   Therefore, it is our position to:

   a. Encourage the provision of services at the local level so that all disabled persons will be able to be served in a community based program regardless of the severity of the handicap or complexity of the needs.

   b. Encourage local programs to plan and support a "zero reject" orientation toward persons in need.

   c. Encourage the provision of services as close to home as possible and in an environment which imposes the minimum stigma and external control upon each individual.

   d. Encourage the prevention of all unnecessary admissions or readmissions to institutions.

   e. Encourage the provision of services in the "least restrictive alternative."

2. <u>To encourage the provision of an array of specialized services which meets the needs of Minnesotans from birth until death</u>.

   Therefore, it is our position to:

   a. Give early intervention primary consideration.

   b. Encourage communities to develop a full range of services to meet the developmental and human needs of all persons with developmental disabilities.

   c. Encourage the provision of services which are specialized to meet unique needs.

   d. Encourage the involvement of separate and different settings and locations consistent with the function of the services (vocational programs in industrial settings, residential programs in residential settings, etc.).

   e. Provide proper linkages, continuity and cooperation between elements of the service system in such a way as to minimize barriers that interfere with clients receiving proper care.

f. Encourage the provision of access to appropriate services without regard to the nature, severity or multiplicity of needs, and without regard to race, sex, physical handicap, age or economic status.

3. To promote the development of services for developmentally disabled persons through the use of generic resources and settings available to all citizens.

Therefore, it is our position to:

a. Advocate for the rights of our clients to use the same resources and settings which are available to all citizens, whenever those resources and settings are appropriate to meet the individual's needs.

b. Coordinate with programs in the community to identify needs of persons with developmental disabilities, identify roles and responsibilities of agencies, and develop a plan for meeting service gaps.

c. Encourage "direct services" only to eliminate gaps within existing programs.

d. Promote the integration of developmentally disabled people into the community in all facets of their lives.

e. If necessary provide training and resources to staff and generic agencies who will serve developmentally disabled people.

f. Make information available to consumers, parents, and staff on community resources.

4. Through the use of individualized program plans, to develop the skills of developmentally disabled people so that they may participate in and contribute to their community.

Therefore, it is our position to:

a. Encourage counties to provide clients with appropriate individual service plans based on an adequate assessment of needs.

b. Encourage providers to give opportunities to develop in clients their potential to become more self-sufficient and to attain self-confidence and dignity.

c. Encourage the state and county to provide the appropriate protective and follow-along services when needed.

d. Recognize that each person is unique, and be responsive to the individual differences and needs of our clients.

e. Utilize modern, well-researched, effective and humane educational and therapeutic techniques, services and service models.

f. Develop programming for each individual, rather than for groups or facilities.

g. View developmentally disabled persons as rightful members of the community, with strengths as well as weaknesses, and always with potential for growth, participation, and contribution.

h. To increase the individual's competence in the areas of independent functioning, economic activities, physical development, vocational skills, domestic activities, cognitive skills, language and communication, socialization, responsibility and self-direction.

i. To reduce the frequency of socially unaccaptable behavior such as violent and disruptive behavior, withdrawal, anti-social behavior, and self-abusiveness.

5. To support and assist families in meeting the needs of the developmentally disabled family member.

Therefore, it is our position to:

a. Maintain the family relationship through childhood, including adolescence.

b. Provide support for adult growth and independence as normal as possible.

c. Coordinate with families to identify developmental disabilities, identify roles and responsibilities of the family and the agencies, and provide assistance directly to the home whenever appropriate.

d. Provide or procure training, if necessary, to assist families in meeting the specialized needs of the family member with a developmental disability.

e. Make information available to families on the resources available within the community to meet the needs of the developmentally disabled person.

f. Provide "direct residential services" only when assistance provided to the natural home is determined to be inappropriate.

g. Aid the family in recognizing the disability as an independent event, not a negative reflection on the family nor the developmentally disabled individual.

6. To increase the public's understanding of the ability and needs of persons with mental retardation.

Therefore, it is our position to:

a. Improve the image and acceptance of disabled (and potentially devalued) people through the education of the public. Recognize that social perceptions and prejudices may be as limiting as the individual's developmental disability.

b. Recognize the contributions made by disabled persons to their own community through public education activities.

c. Focus on the special needs of disabled persons and their families through public education.

d. Provide public education in a manner which will enhance the image of persons with developmental disabilities.

e. Respect the rights and dignity of each individual in public education activities.

7. To advocate for the rights and responsibilities of citizenship for developmentally disabled persons.

Therefore, it is our position to:

a. Encourage the provision of services in such a way that each person has the opportunity to exercise as many civil, legal and human rights as possible.

b. Support clients in exercising maximum responsibility for their lives so that they may function as autonomously as possible and participate in decisions regarding their lives to the greatest possible extent.

c. Provide services in the least restrictive manner possible.

8. To provide staff with the support and training necessary to fulfill their professional responsibilities.

Therefore, it is our position to:

a. Encourage systematic recruitment of high quality professional staff and help all employees improve their ability to perform their jobs through education and training.

b. Encourage the provision of steady employment at a salary commensurate with the service provided by the employee.

c. Encourage the provision of pleasant work surroundings including a safe and healthful working environment.

d. Encourage the provision of opportunities for advancement to existing personnel.

9. To provide an administrative structure which is consistent with the purpose, goals and postions of the Governor's Planning Council on Developmental Disabilities.

Therefore, it is our position to:

a. Encourage state agencies to provide for an equitable distribution of services.

b. Encourage state agencies to provide policy and program standards in order to maintain the quality of services.

10. To provide for a systematic planning, evaluation, review, assistance, and resource development process consistent with the purpose, goals, positions, and priorities of the Governor's Planning Council on Developmental Disabilities.

Therefore, it is our position to:

a. Plan in such a way as to place the maximum decision-making power as close to the client as possible.

b. Encourage monitoring systems to ensure that rights are protected and habilitation needs are being effectively met.

c. Plan in cooperation and coordination with the planning efforts of existing and ongoing planning groups within the Department of Energy, Planning and Development and other state and local agencies.

7414 N. Crossway Road
Milwaukee, WI 53217

August 15, 1984

Mr. Roderick DeArment
Committee on Finance
United States Senate, Room SD 219
Washington, D.C. 20510

Dear Mr. DeArment,

Please add the following to the testimony given in Minneapolis on August 13, 1984 regarding S2053, "The Commnity and Family Living Amendments of 1983".

We are strongly in favor of the bill and urge that it be reintroduced as revised when the Senate reconvenes.

As parents of a thirty year old man who is severely retarded, we are well aware of the gaps in the community service system, largely due to lack of funds. We also know well, how important it is to our son and his peers to be able to be a part of the community.

(He was institutionalized briefly as an infant but we, thankfully, were able to bring him home at age 15 months and have been working hard to develop community services all of his life.)

We know that his life is far richer than it would have been in an institution. We also know that it could be more fulfilled if there were adequate funds for programs that would enhance his development toward greater independence. And he is one of the fortunate ones - there are those in our communities who don't have even minimal services.

S2053 addresses those inequities. Therefore, we are convinced that passage of this bill as revised is essential.

Sincerely,
Dick and Mary Murphy
Mr. and Mrs. R. J. Murphy

Mr. and Mrs. James C. Murphy
515 W. College Ave.
Waukesha, Wis. 53186

Dear Mr. Frederick De Clement,

I'm writing about the Bill S 2053. Title "Community & Family Living Amendments of 1983." This bill would affect our child John Charles Murphy, in this way, he has been at Southern Center in Union Grove, Wis. for 17 years, those years he was toilet trained, he now eats just about everything, he barely ate anything at home. He would regress if taken out, John loves it there, He can't talk, read or write, very little hearing. We are strongly against this bill. John has the hospital, doctor's, nurses, aides, watched ing clearly they care about John Jonathan Kirk is a wonderful young player. Please do not pass this bill. Thank you.

Sincerely
Mr + Mrs. James C. Murphy

N

August 10, 1984
Dodgeville, Wisc.

Dear Mr. De Arment,

This is a letter regarding the bill S-2053 entitled Community and Family Living Amendment Act.

Our Son is a profoundly retarded person and lives at Central Colony - Madison, Wisc.

We feel Central Colony is the best facility for him and superior for care and medical help than would be obtained in a Community Group Home.

We feel it would not be right for him to be in a Community Group Home.

Therefore we are strongly opposed to bill S-2053.

Sincerely,
Mr. & Mrs. Kendall Nelson
Parents of a profoundly retarded Son

Milwaukee, Wisconsin
August 16, 1984

Mr. De Armont

Senator David Durenberger, Chairman
Subcommittee on Health
375 Russell Senate Office Building
Washington, D. C. 20510

Dear Senator Durenberger:

Since I was unable to attend the regional hearing on Senate Bi 2053, the Community and Family Living Amendments of 1983, which I understand was held in Minneapolis of August 13, 1984, I am providing this opinion. I respectfully request that it be made a part of the hearing record.

My wife and I are parents of Deirdre O'Donnell, a profoundly retarded adult, aged 44 years, who has resided at Central Wisonsin Center for the Developmentally Disabled, at Madison, Wisconsin, for over 25 years. Previously, she was a resident of the Southern Center in Wisconsin. Deirdre has a mental age of approximately seven months. She is also severely physically handicapped.

I have made a thorough study of Senate Bill 2053, and have become convinced that it should not be enacted without the adoption of a number of amendments, as attached hereto.

I offer these amendments based on extensive experience in the mental retardation movement over a period of 30 years, which included volunteer service as Chairman of the Governor's State Planning and Advisory Council on Developmental Disabilities, President of the Milwaukee County Association for Retarded Citizens, President of the Wisconsin Association for Retarded Citizens, member of the Board of Directors of the National Association for Retarded Citizens, and numerous other offices.

For their information, I am sending copies of this cooresopndence to other individuals who are interested in Senate Bill 2053, as indicated.

Sincerely,

G. L. O'Donnell

George L. O'Donnell
4961 N. Woodruff Ave.
Milwaukee, Wisconsin 53217

STATEMENT OF PRINCIPLES AND RECOMMENDATIONS FOR AMENDMENT CONCERNING SENATE BILL 2053

STATEMENT OF PRINCIPLES

1) Medical Assistance currently being received by mentally retarded citizens as a result of their legal entitlements, as defined in 1905(a) of the Social Security Act, should be continued. No aspect of the proposed Section 1918 , as contained in Senate Bill 2053, should place these benefits at risk in order to achieve alternative service arrangements.

2) Service arrangements, such as group homes or "community living facilities", should be obtained on the basis of their own merit, not on the basis of an indiscriminate condemnation of a whole category of existing services for mentally retarded citizens.

3) Legislation supported by the ARC movement should contain appropriate provisions to ensure that the basic civil and human rights of all retarded citizens are protected. Steps should be taken to include these rights as a basis upon which appeal of administrative rulings may be initiated. This should include procedures for adjudication by the appropriate courts of jurisdiction.

4) An array of residential services should be provided for mentally retarded citizens which is designed to meet the needs of the individual, after careful and comprehensive evaluation of all the pertinent factors involved.

GENERAL RECOMMENDATIONS FOR AMENDMENT OF SENATE BILL 2053

1) Modify the wording contained in Senate Bill 2053, for paragraph (45) of Section 1902(a) of the Social Security Act, to provide that all mentally retarded citizens currently under legal entitlement to receive medical assistance, as specifically defined in section 1905(a) of the Act, will retain this entitlement, in addition to the "medical assistance" entitlement which is proposed under the terms of Senate Bill 2053.

2) Delete all references in Senate Bill 2053 to the effect that severely disabled individuals may receive medical assistance "only" if they reside in a "community or family living facility".

3) Delete restrictions which Senate Bill 2053 seeks to impose to the effect that severely disabled individuals may be served in various institutional facilities for a maximum of only two years, and may also receive only certain specified services.

4) Delete Section 7, paragraph (b), of Senate Bill 2053. Omit various exemptions for facilities which are based on the number of beds contained therein. Omit the requirement that the number of severely disabled individuals residing in an intermediate care facility or institution for the mentally retarded shall be "reduced to zero", on a firmly scheduled basis, by a specified date. Eliminate the requirement that reports as to progress in this regard shall be submitted "every six months" until the "zero" objective is achieved.

5) Add specific procedures to provide that appeal to the courts may be made concerning decisions relative to the transfer of severely disabled individuals from intermediate care facilities or institutions for the mentally retarded to "community living facilities" in cases where violations of the civil or human rights of the individual are involved.

6) Add more specific information to clearly define the term "severely disabled individual". In the absence of a more specific definition, amend the bill to indicate that it applies to "mentally retarded citizens", and apply standard definitions for these purposes.

SPECIFIC RECOMMENDATIONS FOR
AMENDMENT OF SENATE BILL 2053
(U. S. SENATE, 11-4-83)

JUNE 21, 1984

1) Page One. Change lines 17 to 20, inclusive, to read as follows: "(45) provide that a severely disabled individual who is entitled to medical assistance under such plan shall continue to be entitled to such medical assistance ,as defined in section 1905 (a), in addition to any entitlement for medical assistance which may apply as a result of the definitions and requirements established under Section 1918."

(This change is intended to insure that no severely disabled individual currently eligible to receive medical assistance, as defined in the Social Security Act, will lose his or her eligibility for that medical assistance as a result of the enactment of S-2053. It is also intended to protect current eligibility to medical assistance should S-2053 be enacted, and should any state decide not to participate in the program of "medical assistance", as defined in S-2053. In the latter event, medical assistance would continue under the provisions of current law, Section 1905.)

2) Page 2, line 3. Delete the words, "Except as provided in subsection (b)". Start paragraph (a) with the words, "A severely disabled individual", etc.

(This change omits reference to subsection(b) which is dropped in these amendments. See below.)

3) Page2, line 7. Delete the word "only".

(This change drops the requirement that "only" those severely disabled individuals residing in "community living facilities" may receive "medical assistance".)

4) Page 2, lines 9 to 31, inclusive. Delete these lines.

(This drops the restriction that a severely disabled individual may receive only certain specified services in a " facility other than a community living facility", and then only for a maximum of two years. This is the "subsection (b)", referred to above.).

5) Page 3, lines 6 to 11, incl. Change these lines to read as follows: "(A) All care and services which would have been provided as medical assistance, as defined in section 1905 of the

Social Security Act, if such care and services had been provided to such individual by an intermediate care facility or an institution for the mentally retarded that provides intermediate care facility services prior to the effective date of this legislation."

(This ensures that the definition of "medical assistance", as currently found in Section 1905 of the Social Security Act, also applies to Section 1918, as proposed by S-2053.)

6) Page 5, line 8. Delete the words "severely disabled", and replace with the words "mentally retarded". Page 5, line 9. Insert the word "mental" before the word "disability". Page 5, line 17. Replace the number 50 with the number 18. In addition, replace the words "severely disabled" with the words "mentally retarded" in the following locations elsewhere in the bill. Page one, lines 5 and 17; page 2, lines 2 and 4; page three, lines 2, 19 and 31; page 4, lines 12 and 31; page 6, lines 6,24,25 and 29; page 8, lines 3,8,15,22,and 24; page 9, lines 10 and 19; page 10, lines 5 and 11; page 12, line 22; page 13, lines 23 and 30.)

(This change defines "mentally retarded individuals" as the covered group, rather than "severely disabled indivduals". It is proposed for adoption if the term "severely disabled individual" is not sufficiently clarified.)

7) Page 7, lines 32 to 34, incl. Delete this paragraph (A). Designate paragraph (B) as paragraph (A), and re-designate other paragraphs accordingly.

(This omits the requirement that a state which enters into a "community and family implementation agreement" shall implement the act under the two year time limits specified in subsection 1(b). We have omitted this section. See changes to page 2.)

8) Page 9, line 11. Delete the phrase, "Under the agreement". (This assumes that the state has entered into an "agreement" with the Feds., whereby specific numbers of severely disabled individuals are to be transferred to group homes, on a definite schedule, over a period of time. Under these amendments, this requirement is dropped.)

9) Page 9, lines 17 to 28, incl. Delete lines 17 to 24 incl. Change to read as follows: "(I)(i) that there be developed for each severely disabled individual a community services plan that specifies the types of medical assistance described in subsection (C)(1) that such individual will require should such individual be transferred to a community or family living facility; and"

(The present bill is structured to read that such a plan shall be developed "when" the transfer takes place. The amendment says the plan is developed "should" the transfer occur. It drops the concept of a forced transfer of all residents, but retains the idea of the plan, in the event a transfer is agreed upon.)

10) Page 10, lines 4 to 9, incl. Change these lines to read as follows: "(J) that the parent, guardian, or appropriate family member of a severely disabled individual described in subparagraph (I) is notified in writing that the transfer of such individual from a skilled nursing facility or intermediate care facility or an institution for the mentally retarded to a community or family living facility is being considered at least 60 days before the date such transfer is decided:"

(This changes the wording from a notification that a "determination has been made to transfer" to, in effect, that a change is "being considered". It recognizes the right of the parent or guardian to participate in the decision.)

11) Page 10, lines 10 to 14, incl. Change the wording of this paragraph to read as follows: "(K) that the parent, guardian, or appropriate family member of a severely disabled individual described in subparagraph (I) may appeal such determination to transfer to a community living facility with respect to such individual to an impartial hearing officer designated by the state on the basis that--"

(This change clarifies the right of appeal relative to the transfer.)

12) Page 10, line 26. Omit the word "and". Insert the following third paragraph. "(iii) in the case that an alleged violation of the civil or human rights of such individual is involved as a result of such determination, and appeal to the appropriate federal or state court of jurisdiction may subsequently be initiated; and"

(This adds the civil and human rights of the individual as a basis for appeal, and indicates that such appeal may proceed to the courts.)

13) Page 11, lines 4 to 25, incl. Delete these lines.

(The Section "Temporary Increase in Federal Payments" is deleted. This part provided for increased medicaid payments to residents of a community or family living facility, apparently as an incentive for administrators to speed up transfer schedules.)

14) Page 12, line 33. Delete the words "Except as provided in

subsection (c)". Start with the word "Any". Capitalize the letter "a".

(We have deleted subsection "c" to which this makes reference.)

15) Page 13, line 2. Delete the period. Add a comma, and the following words after the word "Act" in line 2. ", or an alleged violation of the civil or human rights of a severely disabled individual as a result of action taken under this Act."

(This section is "Private Enforcement." The suggested wording provides that any interested party may bring an action to enjoin, not only a "violation of this Act by a State Plan", but also an alleged violation of the civil or human rights of the individual involved.)

16) Page 13, line 5. Delete the period after the word "operation" in line 5, add a comma and the following words,"or in the appropriate state court of jurisdiction".

(The bill currently provides only for actions brought in federal court. The proposed amendment provides for action brought in state courts.)

17) Page 13, lines 19 to 22, incl. Delete entire paragraph (c).

(Paragraph (c) states, "No action may be brought under this section if, at the time the complaint for such action is filed, the same alleged violation by the same State plan is the subject of a pending action in any court in the United States." This paragraph is an obvious attempt to control legitimate legal procedure on behalf of severely disabled individuals, and should therefore be disavowed.)

18) Page 14, lines 18 to 34,incl. Page 15, lines 1 to 30, incl. Delete this paragraph (b) of Section 7.

(This is a very controversial subsection under the title, "Effective Date; Transition." It deals with various exemptions for institutions, depending on the number of beds and date of construction, makes a provison that the number of "severely disabled individuals" must be "reduced to zero" by ten years, etc. This section also requires reports every 6 months to ensure that the states are transferring people out of "institutions", on schedule,etc. These restrictive passages are dropped, because, under the terms of these amendments, they are no longer required.)

STATEMENT OF
NATIONAL RECREATION AND PARK ASSOCIATION
ON S.2053
COMMUNITY AND FAMILY LIVING AMENDMENTS ACT OF 1983
SUBCOMMITTEE ON HEALTH, SENATE COMMITTEE ON FINANCE
AUGUST 13, 1984

The National Recreation and Park Association and National Therapeutic Recreation Society appreciate the opportunity to present this prepared statement to the Subcommittee on Health of the Senate Committee on Finance on S.2053, the Community and Family Living Amendments Act of 1983.

The Association is a national, not-for-profit organization engaged in a wide range of research, education, policy and program initiatives regarding parks and recreation. Our membership consists of some 16,000 individuals, organizations and agencies. These members perform a variety of civic, professional and technical functions to meet America's diverse recreation demands. Many members of our professional branch, the National Therapeutic Recreation Society (NTRS), are employed in the provision of therapeutic recreation services to clients in hospitals, clinics, institutions, schools and community agencies. We have affiliate organizations in each of the fifty states and the District of Columbia. One of the more critical demands we address is the recreation and social needs of America's severely disabled population.

We support the legislative intent of S.2053 to facilitate placement of severely disabled individuals in a least restrictive setting and to maximize their potential for self direction, employability, and community integration. However, we respectfully submit several recommendations for your consideration which we believe will strengthen the proposed legislation.

Because severely disabled persons generally have a limited capacity for extensive and meaningful work experiences, they have a greater need and desire for meaningful "non-work" experiences. Recreation opportunities provide for this. Therapeutic recreation uses recreation services to improve, develop, and maintain functional behaviors, including physical, psyhological, social and emotional behaviors. Therapeutic recreation also assists individuals to develop independent lifestyles.

S. 2053 recognizes these contributions of recreation services towards rehabilitation of severely disabled persons by including in the language of the bill a reference to comprehensive services for independent living as defined in Section 702(b) of the Rehabilitation Act of 1973. Accordingly, recreation <u>may</u> be included as an adjunct service. However, this reference to the inclusion of recreation services needs reinforcing. An option to provide for recreational activities does not guarantee existence of these programs for severely disabled persons.

Although there may be some reluctance to mandate specific services, including recreation, we contend that specifying inclusion of content areas pertinent to functional living skills more readily ensures a comprehensive and sound individual service plan. It also avoids risk of inconsistant and loose interpretation and application of the law. **Therefore, we recommend that recreation services be identified as a specific form of medical assistance provided for severely disabled persons, and that recreation services be cited as a complimentary vocational service that will "enhance the independence, productivity and** community integration" of a severely disabled individual; Section (c) (1) (C) and (D).

Therapeutic recreation services are of a lifelong or extended duration and are best planned and coordinated on an individual basis. Therefore, it is imperative that professionals trained in providing therapeutic recreation services, including elements of therapeutic intervention, leisure educcation and self-initiated recreation, have direct input into development of comprehensive individual treatment plans for disabled persons. **Therefore, we recommend that therapeutic recreation specialists be part of any interdisciplinary team which develops individualized service plans, and that therapeutic recreation service be specifically identified as a component of all individualized treatment service plans; Section (h) (2) (D). Further, we recommend that wherever possible only therapeutic recreation specialists certified by the National Council on Therapeutic Recreation Certification, an independent certifying body, be part of the interdisciplinary teams to ensure quality evaluation and development of individual service plans appropriate to the needs of severely disabled individuals.**

The proposed legislation recognizes that the quality of service provided to disabled persons in institutions or community-based facilities depends largely on the education, skills and experience of the service providers, and includes language in S.2053 supporting continued training and retraining of all staff of a community and family living center. **In order to strengthen this section we recommend that rehabilitative service areas be specifically listed as requiring continuing training or retraining, and that therapeutic recreation service be included in this list; Section (i) (1) (c).**

Independent monitoring of the quality of medical assistance provided for residents of community and family living centers is critical to the success of the program. In August, 1984 separate investigations by the Secretary of the Department of Health and Human Services and the Chairman of the Senate Subcommittee on the Handicapped reported neglect and abuses in rehabilitation and treatment in intermediate care facilities for mentally retarded (ICF/MR). Residents in these centers were found to have been deprived of several of their civil rights, including access to therapeutic recreation services. Abuses such as these cannot be tolerated. To strengthen this section of S.2053, we recommend that "periodic independent monitoring" be more clearly defined. Specifically, we recommend that independent monitoring of community and family living centers be conducted at least once each year, and that the monitoring team consist of professionals representing desciplines associated with providing medical assistance services which would include therapeutic recreation specialists; Section (i) (1) (F).

In summary, this statement has commented on five (5) major areas of S.2053, the "Community and Family Living Amendments Act of 1983. We believe these five areas need strengthening to best serve the needs and interests of severely disabled persons. In brief, our recommendations include:

1. Specific identification of recreation as a distinct form of medical assistance.

2. Inclusion of therapeutic recreation specialists on interdisciplinary teams which develop individualized treatment service plans. Certified therapeutic recreation specialists would be utilized, wherever possible.

3. Identification of therapeutic recreation services as a component of all individualized treatment service plans.

4. Continuing training and retraining of therapeutic recreation specialists serving on staff of community and family living centers.

5. Monitoring of quality assurance plans at least once each year, by independent teams of qualified specialists that include therapeutic recreation specialists.

No doubt that if our recommendations are considered and accepted, recreation and leisure needs of disabled persons will be well served. It is clear that a majority of our Nation's disabled persons require such service. Without specfically providing for therapeutic recreation services in community and family centers, such services cannot be guaranteed. It would be a mistake to assume that local recreation agencies are currently capable of serving the needs of the severely disabled. Today, few communities have been able to meet the total recreation demands of their disabled public, much less the recreation needs of the severely disabled.

The National Recreation and Park Association supports the effort to identify the least restrictive environment for all disabled persons. We believe that S.2053, the Community and Family Living Amendments Act of 1983 will be strengthened by incorporating our recommendations as outlined in this statement. We appreciate the opportunity to comment on this proposed legislation. Our organization, staff and membership stand ready to assist in any way possible to ensure meaningful lives for severely disabled individuals.

8-27-84 O

Dear Mr. De Arment;

I am writing this letter to you regarding bill # S. 2053 on which a hearing was held in Minneapolis, Aug. 13, 1984, by Sen. Durenberger. The bill is "Community and Family Living Amendments of 1983."

A little about our own family and how our handicapped son has been affected by care at C.W. Center for the Developmentally Disabled.

No parent can put into words the feelings they experience when told their child will be handicapped and most likely not develop mentally beyond a 3mo. level. Also, no one can know the feelings of determination to prove perhaps there was an error made, only to find out the original diagnosis was correct. Our son was our second child and was diagnosed after tests were done at a hospital in a new area we recently moved to. was, just days before we found out we were expecting our third child within six months. We were immediately advised to place our son in an institution (that was almost 20 yrs ago). We refused this alternative and I felt the Lord would show me in some way if I could no longer provide the care Jim needed. After six difficult years of constant care, that message came when I was several months pregnant with our fourth child. I was very big and Jim was also growing and I could no longer lift and move him easily. It was at my gynocologists' suggestion, that we agreed to consider placement for Jim at this time. We hoped he'd get the care (medically for his seizures) & physical therapy etc, and have all his needs met. I must say this was the most difficult decision we've ever made in our marriage, but we have always felt it was the best one for Jim! He's done so well there and even improved to where his attention span

2

is increased; he's as happy as he was at home, and is always clean & in good health. When he needed surgery it was taken care of as soon as it was recognized & his needs are always known, and medication, therapy etc are provided by qualified & very competent people. The social workers are friends and the workers are truly "special people." The Foster Grand-parent is also very special - all things he could not have experienced at home as in the small community living.

I've told many people that if tax payers truly wanted to see their money spent wisely that they need only visit C. Wis. Center in Madison!

It is our hope that these poor helpless individuals will continue to receive the care they are now receiving where they are receiving it. It isn't that we don't want them - but we want the best for them & they have the very best now!

Tax cuts can be made in areas where people can defend their own rights (such as prisons welfare etc.) but please don't take away the only security they have and the right to good health care!

Thank You for hearing me out. We cannot ever fully express what we feel on this subject, so much more enters the picture, but we hope this will bring one small hope that bill #S.2053 is torn up and put in the trash barrell where it belongs!

P.S. Have you personally
visits one of these centers.
It's inspiring!

Sincerely,
Mrs. Brian Oehler
4330 Springwood Dr.
Wisconsin Rapids, Wi 54494
(715 424-3593)

WRITTEN TESTIMONY PREPARED FOR ADOPTION BY PARENTS ORGANIZATION OF OAKWOOD TRAINING CENTER

The writer began attending the annual family day at Oakwood in 1976. We took two or three years to get the sponsoring organization constituted and have had five presidents since then. So this statement covers about nine years, 1975-1984. During this time we have seen Oakwood in operation and have learned what is happening in the field of care for the retarded here and in the state and nation.

Members of PROOF are broadly representative of the people of our state and mostof them are parents or near relatives of the residents of Oakwood. As we have been associated together over several years we have learned of the concern of our members and their eagerness to help find and maintain adequate prpvision for our residents and other retarded persons.

Our stated purpose from the constitution , adopted May 20,1978, is:

a. " To promote the general welfare of exceptionally handicapped persons wherever they may be.

b. To assist the Oakwood Training Facilities in the development of programs in their behalf.

c. To advise and aid parents or relatives in the solution of their problems and to coordinate their efforts and activities.

d. To develop an understanding of the problems of mental retardation by the public.

e. To serve as a medium for gathering and giving out information regarding the exceptionally handicapped.

f. To cooperate with state and national agencies or associations to promote the common cause. (Continued)

g. To cooperate with all public, private, religious, and professional groups in achieving these purposes.

h. To solicit and receive funds for the accomplishment of the above purposes."

By wise leadership and good fortune our first three presidents were elected to serve on the Developmental Disabilities Council of Kentucky.

One of these presidents told us of his concern that the trend in the state and nation was to close institutions in favor of community programs. Since we all put a high value on the services given our residents at Oakwood, we resisted this movement with considerable unanimity and solidarity. Parents of other institutions in Kentucky sounded out the message that this movement had gained great headway in our state and urged us to redouble our resistance. We did this with enough effectiveness, we hope, as to get the attention of the state professionals.

Two other former presidents became members of the DDC and they have found a better climate for understanding and friendly dialogue between the concerned parents and the state Cabinet of Human Resources and their appointed officials and specialists.

PROOF, our Oakwood parents organization, has learned by observing Outwood at Dawson Springs in western Kentucky and Hazelwood in Louisville, where some of our multiply handicapped are. We have met and talked with parents of both of these, shared their concerns and learned from their experiences. We've attended meetings with them, at which government personnel and others have spoken. We have read about, studied and written letters about proposed Kentucky and federal legislation affecting us.

(Continued)

In all of this experience we have come to feel with other parents like ourselves, and it all adds up to a growing concern that our state and nation are being led to close large institutions for the retarded, as they have already done for the mentally ill.

Further we have felt the call to speak up for the hundreds, who on a national scale are part of the thousands, who need our institutions to remain in full operation.

We realize our unpreparedness to lobby adequately to stem the tide, but we are emboldened to believe that our cries are being heard by our professionals and legislators and that they will not turn a deaf ear to our testimony. We must have our Oakwoods, Outwoods and Hazelwoods in order to face the future.

Therefore, be it resolved this family day, August 12, 1984, that we present this plea, with other like expressions from individuals who may join us to our elected officials with gratitude for their attention and consideration.

ADOPTED BY THE PARENT-RELATIVE ORGANIZATION FOR OAKWOOD FACILITIES, INC.(PROOF) AT FAMILY DAY, AUGUST 12, 1984.

Somerset, Kentucky
42501

SIGNED Robert L. Palmer
PRESIDENT

SECRETARY

August 16, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, D.C. 20510

Re: Bill S 2053
"Community & Family Living Amendments of 1983"

Dear Mr. DeArment:

I wish to voice my strong objection to Bill S. 2053. I am the mother of a profoundly retarded and physically handicapped son, Brian Parkinson, age 22. Brian has resided at Southern Wisconsin Center for the Developmentally Disabled at Union Grove, Wisconsin for the past 16 years. The last eight years he has been cared for in the chronic section of Wallace Hospital at Southern Wisconsin Center.

Brian needs twenty-four hour total nursing care. He is non-ambulatory, non-verbal, suffers epileptic seizures, and must be fed, bathed and diapered. The placement of Brian at Southern Wisconsin Center has been determined for him each year when a review of his needs has been made. A community group home would be unable to meet his intensive care needs. On my weekly visits to see him I have been able to observe the excellent care he has received.

I am a widow, 64 years old, and most concerned about Brian's future. I cannot emphasize too strongly my objections to this bill as I feel it is not in the best interests of my son who cannot speak for himself.

Sincerely,
Rosemarie K. Parkinson

Rosemarie K. Parkinson
4463 North 73rd Street
Milwaukee, WI 53218

2221 El Cejo Circle
Rancho Cordova CA 95670

Mr. Roderick DeArment
Chief Counsel & Finance
United States Senate
Room SD 219
Washington, DC 20510

Dear Mr. DeArment:

Please consider this letter as Written Testimony for the hearing on S. 2053; "Community & Family Living Amendments of 1983.' I am totally against this proposed legislation.

My daughter, Kathleen Joan Parr, has been a resident of Southern Wisconsin Colony since 1965. She is severely retarded and is subject to major motor seizures. She requires 24 hour medical care and supervision. She has been receiving the best of care all these years. This is the only consolation I have.

There are so many newspaper accounts of retarded residents, in community homes, who are not only neglected, but, in some cases, sexually abused! Naturally I find this alternative frightening.

I urge you to vote against this bill for the sake of my child and the hundreds more like her.

Sincerely,

Joan E. Parr

cc: Senator John Chafee
Mr. Paul Marchand
Senator David Durenberger
Mrs. Dee Everitt

Ms. Mary Ann Parrish
7401 W. Tripoli Ave.,Apt.4
Milwaukee, WI 53220
Tel:(414)327-6844

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

RE: HEARING ON S.2053

Dear Mr. DeArment:

I am writing to you regarding the above bill of Senator Chafee's.

It would be a gross injustice to our moderately and severely retarded children to place them in group homes or the like. My son was the victim of placement. After 8 group homes, with people who were not qualified in handling the retarded plus the fact that my son could not adapt to a group home setting (and there are plenty of these), he was placed out in the Mental Ward of the State Hospital here in Milwaukee, WI, because there was no place to put him since he was no longer in the institution and could not fit into the group setting. Believe me Mr. DeArment, it was like a nightmare! My son was afraid to be out there, I was afraid for him, the doctor out there was mad because he did not belong there and the doctor did not know what kind of effect this would have on my son in the years to come. I called everyone, everywhere, I wrote to everyone and I finally wrote to Senator Proxmire and God Bless him he helped me get my son back into the colony. I don't know what I would have done without his help.

An article was written about my son in the Milwaukee paper about our dilema entitled "ON A BRIDGE TO NOWHERE" and that is exactly what it was ---a bridge to nowhere!

These children are handicapped--most cannot function on the outside. We have institutions for dogs and cats, we don't let them wander about. PLEASE PLEASE I hope with all my heart that everyone who is considering this bill stop to think of the outcome of what will happen. It will be devasting!!! The institution setting gives them a sense of security-they need this. They provide very good care and recreational plus religious and regular schooling.

The few that are mildly retarded may be able to function outside---but the ones that can't far outnumber the ones who can.

ON BEHALF OF ALL THE HANDICAPPED CHILDREN ---PLEASE DON'T DO THIS TO THEM.

The change in my son upon re-entering the institution was unbelievable/ remarkable. PLEASE DON'T PASS THIS BILL

Sincerely,

Mary Ann Parrish

Patient

Retarded man stranded on a bridge to nowhere

From Page 1

other's lease expired, Scott was moved six more times.

By then he had begun "acting out," as the social workers say, and there were some incidents of physical aggression and hostility. Last month, after four weeks in his seventh group home, he allegedly attacked the house parent. He was taken to the psychiatric emergency ward at the County Institutions.

New Concepts doesn't want him anymore, because he no longer is considered appropriate for one of its group homes. Southern Center, which has a much smaller program for severely and profoundly retarded persons, won't take him back, either. State policies of the last decade called for hundreds of residents to be removed from institutions and placed in the community.

About 1,300 retarded people who once lived at the state center now live in nursing homes in the Milwaukee area. According to present thinking by professionals in the field, few belong there, and many are in some ways worse off than they were in the state institution.

But whatever the merits of such placements, there are no vacancies in nursing homes for a retarded person with Scott's history of behavior problems.

Weekend haven

His mother's home is a weekend haven, not a permanent solution. A divorced executive secretary with two other children, she said her job and Scott's unpredictable behavior made a permanent solution impossible. Several professionals involved in the case agreed.

"It's just tragic," she said. "This is the cruelest thing they could have done to him.

"They fought and gave the mentally retarded their rights. They took my son out of an institution where he was doing well, and he was learning, and he was never aggressive.

"He has not progressed in two years. He has been miserable for two years. And then they put him in a psycho ward. That's the worst violation of his human rights."

She has been calling officials in the human services system for a month in an effort to find another placement for Scott, all the time increasingly angry and desperate about the effect of the mental hospital on her son.

"Scott may be mentally retarded, but he has feelings, and he's scared," she said. "The whole thing has made him so nervous and bewildered and upset, he keeps saying, 'Mom, I'm going to die. Mom, I'm going to die.' It's his way of pleading, 'Get me out of here.'"

Michael Beal, the psychiatrist in charge of Scott's psychiatric ward, said Scott was admitted "as a humanitarian gesture" because there were no alternatives.

Scott's not unique

Scott is far from unique, Beal added. Another patient who is profoundly retarded and has little or no speech has been 21st on Southern Center's waiting list for 1½ years, he said.

Beal estimated that 10% of the patients in the hospital's acute wards, about 18 persons in all, were retarded individuals who were not mentally ill and could not benefit from hospital treatment but had nowhere else to go.

At the same time, Beal noted, the hospital is at 110% of capacity and under constant pressure to admit more patients.

"That's a moral question that I struggle with a lot," Beal said. "It's a question of choosing between two evils — discharging people who can't care for themselves, or on the other hand not being able to admit somebody who could better use the bed."

There is another paradox involved. The inpatient hospital rate is $106.83 a day. On the other hand, a local foster-care program for mentally retarded adults that costs a fraction of that has been halted because the state money for it ran out.

"That's what's so insane about the system," said Mary Coffee, a senior planner with the Planning Council. "We have such a limited number of options that we're always acting out of desperation. We don't focus on what Scott needs; we focus on what's available and where there's funding."

Coffee sharply rejected Scott's mother's nostalgic view of Southern Center as providing a campus-like environment where retarded men and women learned, played and had security.

"It's just because people are so depressed and disgusted by what the community doesn't have that they're turning back to Southern Center," Coffee said. "I used to work there. I can remember asking staff where a resident was and being told, 'I don't know; he was here at feeding time.'

"Southern Center is very limited in what it can offer. And the staff is not trained to deal with disruptive people. All they can do is medicate them."

But Coffee, who worked in community placement at the center, acknowledged that many former residents were, at best, no better off now.

"I feel very haunted sometimes when I think of the people I placed in nursing homes," she said. "At the time the nursing home staff seemed to treat them like people. But the staff burn out, things change. . . I think about those people now."

Scott never really had a chance to adjust to a group home, an advocate from the United Association for Retarded Citizens argued. But now, the advocate, Cherie Calewart, acknowledged that it was probably too late for that kind of program.

A helpless feeling

Calewart searched for an alternative, even consulting a lawyer about the possibility of suing the county for services.

"I ended up feeling pretty helpless myself," she said.

John Ross, regional director of New Concepts Foundation, a private, non-profit agency, first questioned the appropriateness of Scott's initial release from Southern. Then he said:

"If I stand back from what has happened, I can say some errors were made with Scott. . . . I'll admit that we were guilty in moving Scott as much as we did . . . . but it was beyond our control."

The agency had to learn that group homes, which work well for some retarded adults, would not work for others, he said.

Bad behavior

He said one of Scott's group homes had been designed to serve retarded people with emotional or behavioral problems, but it turned out that residents learned bad behavior from one another, and house parents wouldn't stay on the job.

That program concept was abandoned, and the six residents dispersed. Two are now in regular group homes, Ross said, but the other four, including Scott, are in institutions — one in jail, one back at Southern Center, one in a nursing home.

"We have moved away from quantity to quality," Ross said. "I guess there still have to be mistakes like what happened to Scott to reinforce the need for quality services."

Variety needed

Advocates for the disabled and policy makers within the Department of Health and Social Services are talking about the need to create a variety of community living options for persons who, like Scott, need lifelong supportive help.

There is discussion of possible mechanisms to take the Title 19 Medicaid money that now goes for expensive — and inappropriate — care in nursing homes, and to give it to local communities to spend on other options ranging from one-to-one live-in assistance in an apartment to small adult residential treatment centers.

But in the real world, Gov. Dreyfus' 4.4% cutback probably means a freeze on any new housing for the retarded, or any expansion of previous programs, including Southern Center.

"They've made a mistake," Scott's mother said. "They have to correct the mistake. These are human beings. They're not construction. They are not a highway. They are human beings."

On a bridge to nowhere

By Nina Bernstein
of The Journal Staff

"Scott keeps saying, 'What's going to happen to me, Mom? What's going to happen to me?'

"When it's time to take him back, he says, 'Mom, I don't want to go back to the ward. Please, Mom. . . .'"

Mary Anne Parrish doesn't know what to tell her son. How do you explain to a 22-year-old man with an 8-year-old's mind that he is the victim of a system in transition, a casualty of mistakes that may now be past correcting?

Scott, who lived from age 7 to 20 at the state's Southern Colony — now Southern Center for the Developmentally Disabled — is one of hundreds of mentally retarded people who were stranded on bridges to nowhere when the blueprints changed and the money ran out.

For the past month, he has been living in an acute psychiatric ward at the Milwaukee County Mental Health Complex, where doctors say he does not belong because he is not mentally ill.

There is simply nowhere else for him to go.

When Scott was discharged from the state institution two years ago, his mother said, he was an affectionate, trusting person with no aggressive tendencies.

Then came placement in a series of Milwaukee-area group homes. In the first, Scott's mother said, he was mistreated by a house parent who ultimately was fired by the sponsoring agency.

Scott, fearful and upset, then was placed in a group home of a second agency, New Concepts Foundation. As two sets of house parents quit, as one group home program was abandoned and an-

Turn to Patient, Page 16

Aug. 14, 1984

Dear Mr. DeArment

I'm writing this letter to indicate my strong disapproval of Bill S 2053, the " Community and Family Living Amendments of 1983." I have a severly retarded son who has been living at Southern Wisconsin Center for some time and I can testify to the fact that he gets good care. He, as well as the other residents, are kept busy in either school, workshop or in cottage craft room. Surroundings are bright and cheerful and clean. As of now our city of Milwaukee has no facilities to keep the severly retarded busy, and I doubt that many cities have.

I have a copy of the original bill which has no provisions for health care, a vital consideration, since most of the severly retarded have multiple health problems At the institution there is a nurse in every building and a doctor on the premises, also a hospital. This can't be disregarded.

The Center's buildings are in what looks like a huge park. Our children can be outside and are safe. If they lived in cities they would be surrounded by streets, which would pose a real danger if they tried crossing them. Therefore they would be quite restricted.

Some years ago it was decided to try my son in a group home even though he was not as capable as the other residents. This gave me the opportunity to see how unstable a group home can be. The first of houseparents, who had things going pretty well, quit and two elderly women were hired. From then on things deteriorated quickly. My son can neither read or write. He became separated from the others coming back to the group home by bus from J.V.S. and was alone and lost for several hours into the evening on a winter night. He was picked up by the police in a suburb of the city. Right after this incident his behavior became bisarre and he regressed to a great degree. This regression has never reversed itself.

We, the parents of these severly retarded children, love them, are close to the situation, and really do know what is best for them. I beg you to listen to ours pleas.

Sincerely,
Marie Pernusch
3291 N. 48th St.
Milwaukee, Wi. 53216

P.S. Enclosed is a letter I wrote which was published in the Milwaukee Journal

81.3/84 P

Dear Mr DeFrmont:

I'm writing to you in regard to Bill number S. 2053 "Community & Family Living Amendments of 1983".

I'm sure you feel this was good bill, but my child could never live in a group home. He is classified as severely retarded & he needs the kind of care only the institution can give him. He is at Southern Colony. He could not dress himself or do anything. The teacher that he has now has really brought him a long way more than I ever thought he would be able to do. It is very hard to put your child in an institution, but he gets such good care & love there that it helps me quite a bit to accept it. You really don't know what it's like unless you have a retarded child. There are some that could possibly live in a group home but the greatest majority of them really need a place like the Colony.

I feel that this bill would really do more harm than good for these children. They are with their own kind & get the care & attention & constructive help they need at the Colony.

Being a parent of a retarded child & seeing what the Colony has done for my son I definitely feel that the Colonys are the only places for the most of these children

II

Please reconsider this bill & do what is right for our children & leave them at the belongs where they get the care & help that they need.

Seeing my son there & knowing that he is happy eases the hurt in my heart as much as is possible. I know he is loved & taken care of properly & gets the help he needs.

Thank you for your time.

Sincerely

Mrs Joyce Pi

Dear Mr De Armant! aug 13 P

THIS LETTER IS IN REGARD TO BILL S.2053(COMMUNITY AND FAMILY LIVING AMENDMENT OF 1983: OUR DAUGHTER IS 25 YRS OLD, HAS NO SPEECH OR HEARING, DIFFICULTY WALKING AND CHEWING FOOD, SEVERE LOSS OF MUSCLE COOORDINATION IN HANDS AND WRISTS, AMONG MANY OTHER PROBLEMS. AT THE AGE OF ONE YR. SHE WAS FIRST EVALUATED TO LIVE ANOTHER TWO YRS. NOT TO SIT OR WALK. WELL, THANKS TO THE EXCELLENT CARE, DOCTORS, ECT. OF OUR STAT INSTITUTIONS SHE IS ALIVE TODAY AT 25YRS OF. AGE. NO MATTER HOW YOU LOOK AT OUR SITUATION AND MANY LIKE OURS WE DO NEED GOOD INSTITUTIONS. LUMPIN ALL RET. AND HAND. PEOPLE IN ONE LUMP SUM AND SAYING THEY CAN ALL LIVE IN THE COMMUNITY IS NOT ONLY WISHFUL THINKING BUT CAN BE VERY DANGEROUS TO THE WELL BEING OF THAT INDIVIDUAL. GRANTED NOT ALL STATES HAVE AS FINE A FACILITIES AS WIS. HOWEVER THEY ARE NECESSARY . PLACING ALL "PEOPLE" IN GROUP HOMES WILL NEVER WORK. IN THE FIRST PLACE, WHERE ARE YOU GOING TO GET THE STAFF TO HANDLE THE PEOPLE LIKE OUR DAUGHTER WHO NEED CONSTANT CARE AND WATCHING? ALSO NOONE WANTS GROUP HOMES IN THEIR NEIGHBORHOOD. THEY FIGHT THEM AS MUCH AS A PRISON.

BESIDES BEING A PARENT OF A RET. AND HAND. CHILD, I WORKED FOR SEVERAL YRS. AT A LARGE NURSING HOME. I SAW ALOT OF YOUNG ADULTS LEAVE THERE FOR A GROUP HOME, NONE OF THEM MADE IT. I FOUGHT AGAINST THESE(ONE BOY GOT HIT BY A CAR FIRST DAY HE WAS ON THE OUTSIDE HE DID NOT KNOW HOW TO READ A STOP SIGN) AMONG OTHER THINGS.

PLEASE CONSIDER THIS LETTER AND OTHER LETTERS STATING THE TRUE FACTS OF THE MATTER, ITS WISHFUL THINKING TO SAY WE DO NOT NEED INSTITUTIONS, AND CAN BE DOWNRIGHT DANGEROUS TO "OUR SPECIAL CHILDREN".

SINCERELY
NORB AND LAVERN PIERRE
LaVerne Pierre

9523 W Forest Home
Hales Corners, WI 53130

August 20, 1984

Re: Proposed Legislation, U.S. Senate Bill S.2053
Community & Family Living Amendments - 1983

I am writing both as a concerned citizen and as the parent of a profoundly retarded young woman of age 33 who has since birth required extremely special care having been born afflicted by severe PKU amino aciduria disorder. She has very limited speech, comparable to that of a 2½ to 3 year old, which since about 1974 (age 22) her condition became worse due to behavior problems brought on by major motor seizures and schizophrenia. Her daily behavior is such that it would be impossible for her to function in any environment other than that of a closely secured, and 24 hour supervision such as an institution with highly specialized medical personnel.

My daughter was placed at Southern Wisconsin Center at age 7 and remained there until 1973 (age 21) when she was transferred to a private nursing home with so-called "family living" type care. As a result of this placement she developed extremely severe behavior problems due to lack of properly trained personnel and the development of seizures and schizophrenia. (Attacking other residents without provocation, putting her fist through glass doors, etc.) as noted in the preceding paragraph. In other words, it just simply didn't work out, and she was returned to the institution after 3 years' time.

I have enclosed a copy of portions of her 1984 evaluation at the Center, which are self-explanatory.

Based on the above, I am adamantly opposed to the subject legislation, and urgently request that it *not* be supported as proposed, and as it affects those individuals in our society who desperately *need* the care such as is provided *only* in facilities such as Southern Wisconsin Center. My daughter was well cared for, with a minimum amount of problems, before and after her interim placement in this so-called family type arrangement.

As her mother I have had first hand exposure with this type of situation and I *know* that there are those who simply cannot survive in ~~in~~ a "Community and Family Living" type facility.

I *beg* you to *not* lend any support to this Bill as written. There must be places provided for these poor, unfortunate people, who in no way are able to function in a situation which will require them to do what they just simply don't have the mental or physical attributes to do!

Thank you for your help.

Sincerely,
Rosemond Ploetz

SOUTHERN WISCONSIN CENTER FOR THE DEVELOPMENTALLY DISABLED
21425 Spring Street
Union Grove, Wisconsin 53182

1984 MEDICAL SUMMARY

PLOETZ, Cheryl, SWC 4226
Birthdate: 5/18/52
Adm. Date: 2/13/59

DATE: March 8, 1984

AAMD DIAGNOSES:
Mental retardation, profound, due to PKU aminoaciduria disorder. Limited speech. Convulsive disorder, akinetic seizures, R/O major motor seizures. Ambulatory. Schizophrenia, not specified.

Cheryl is a 31 3/4 year old, profoundly retarded, white female. She is a known PKU patient. Originally she was admitted to Southern Wisconsin Center on 2/13/59 at age 7 years. She was in placement from 1973 until 7/26/76. At present, Cheryl is a Cottage 1 resident. She is ambulatory, has very limited speech and understanding. She has limited self-care skills. She is toilet trained. Cheryl can recognize Cottage 1 staff members and her family. She is not aware of time, place and danger. She responds to her name, can follow simple directions, and she interacts with peers. Cheryl's I.Q. is like that of a two-year-old. Cheryl partakes in S.W.C. adult education and recreational programs.

MEDICAL ASPECTS:

Behavior: Cheryl has a long history of behavior problems. Cheryl is a large, strong girl. She has a short attention span. She is unpredictable; her happy mood can alternate with severe temper tantrum outburst episodes or screaming episodes if she is asked to do something she doesn't want to. At times, she bites her hand for attention. She is very resistive.

Many years ago, it was felt that Cheryl was schizophrenic and needed psychotropic medication. It is known that PKU encephalopathy quite frequently is associated with schizophrenia. On 2/7/84, Cheryl's Haldol was reduced because she was unsteady. Her behavior has been about the same.

Seizures: Cheryl is a known seizure patient (since 1976). Seizures started while she was in placement. Her EEG in 1978 was abnormal, compatible with paroxysmal symptoms and diffuse encephalopthy. Cheryl had one seizure in 1982, one seizure in 1983, and three seizures so far in 1984. She has been followed by seizure clinic and was last seen on 2/15/84. In December of 1983, Cheryl's seizure medication was discontinued. After seizure activity returned, seizure clinic restarted her on Depakote.

Menses: No menses recorded in patient's chart. Cheryl was seen by Dr. Gass on 8/18/83. Pap Smear negative.

Genetic Consultation: Genetic consult done 7/20/82 by Dr. Kaveggia (see report).

Audiology: Cheryl had audiological testing on 3/18/82. She was uncooperative during testing. It was felt that she can hear.

Immunizations: Last DT was in 1967. Last tetanus toxoid in 1978. Polio immunization in 1969 (one). TB skin test negative in January of 1983. There is no need for Hepatitis B immunization.

Eye Consult: Routine eye exam was done 5/18/83 by Dr. Pierce, D.O. Cheryl is highly myopic--glasses were ordered.

General Medical: General health is good. Height is 68 inches. Weight is 148 pounds. Physical examination done 3/7/84--not ill. Urinalysis dated 2/22/84 negative. Chest X-ray negative 4/28/84. Cheryl has a tremor in her hand. She has a tendency to gain weight. Cheryl is followed by Podiatry Clinic for foot problems.

CURRENT MEDICATIONS AND ORDERS:

Cogentin 1 mg. at 8 p.m.
Cogentin 2 mg. at 8 a.m.
Haldol 10 mg. at 8 p.m.
Depakote 500 mg. at 8-8
Haldol 5 mg. PRN for disturbed behavior--not to exceed 2 doses in 24 hours
Swimming with one-to-one supervision
Bite-size diet with limited dinner and supper servings.

RECOMMENDATIONS:

1. Medical: Continue current care and treatment. Continue Podiatry Clinic PRN. Observe for weight gain. Continue seizure clinic PRN. Glasses.

2. Continue current programs.

3. Activity Level III.

4. Swimming with one-to-one supervision.

5. Utilization Review Recommendation: No placement recommended and I doubt if any nursing home would want to take her due to her behavior problems. She failed a placement in 1976. ICF-1.

6. Physician Recertification of Need for Continued Inpatient Care: It is hereby recertified that Cheryl Ploetz, SWC 4226, is in need of continued inpatient care because of her behavior problems, aggressiveness, self-abusiveness and noncompliance. It is estimated that the period of additional inpatient care is indefinite. This patient will be reevaluated for recertification in one year.

Gabriella Botka-Wunder, M.D.

GBWmab

TO WHOM IT MAY CONCERN:

Back in 1956, if there had been money for community programs. I would not have had to go to an institution for mentally retarded. And I know myself that coming out of the institution in May 17, 1971, and I was placed on convalescent status in a group home in Grand Rapids. The home had four other residents also from Coldwater. We had a counselor that helped us adjust to life outside the institution. She helped me get a job at Butterwick Hospital in Grand Rapids, and I held that job five years.

I felt that the community placement had played a major role in helping me overcome my years in the institution.

In the day all the changes that have happened in the Michigan Department of Mental Health the institution I was in used to have 3,000 residents and today it is down to 398; and I still say the treatment of mental health services have come a long way, but there is a need for more improvements. There is more for persons in the community and not locked up in the institution. Out of mind and out of reach.

With my own testimony and experience in the institution, I have grew up in an unpleasant life--I was very confused little boy--I was sent off on the ward away from my parents and I was homesickening. Often the staff set us along the wall on a hard wooden bench. A lot of times I just lay around on the hard floor and had a lot of thorazine to keep me quiet.

We had no rights at the institution. I was mistreated, beaten and told I must adjust to the institution style and told this was always going to be my home. People that couldn't do things were called low grades. I was a high grade boy and was made to take care of the low grades. The only good time was when the recreation staff came.

Dollars need to go to the community instead of the institution. The quality of life should be in the community, not the institution. Residents need the chance to prove their skills in the community.

Now I work in the mail room of the Michigan Department of Mental Health and have just moved into my own apartment.

Thank you for letting me express my opinion.

Richard Prangley

Richard Prangley

501 West Leanawee
Lansing, Michigan 48933

(As dictated to my friend, Dorothy Marsh, Association for Retarded Citizens/Michigan.)

110 So. 20th St.
La Crosse, WI. 54601
August 16, 1984

Senator David Durenberger, Chairman
Subcommittee on Health
375 Russell Senate Office Building
Washington, D.C. 20510

S. 2053 Community & Family
Living Amendments of 1983

Dear Senator Durenberger:

This letter relates to the above bill S.2053. We received the notice of the public hearing on this bill in Minneapolis too late to request to be allowed to testify. We feel, however, we must make our views known to you regarding our son, Philip Pryor.

He is cerebral palsied and severly retarded. In addition to having the mentality of a two and a half year old he is in fact a quadraplegic. He has partial use of his right arm and hand. He has been at Central Wisconsin Center for the Dev. Disabled in Madison for over 15 years.

The multi-handicapped, such as Philip, represent only 3% of the retarded population. Some social workers and other do-gooders seem to take the position that if these people are brought back to the community in some mysterious way they will develop and become self supporting. You would not believe how wierd some of their ideas are.

The NARC and local ARC groups are also advocating the closing of institutions. The only reason I can assume for their position is that they feel the institutions are too costly, that for this reason their people get a smaller slice of the pie.

What they do not realize is that these multi-handicapped are going to require custodial care the rest of their lives whether in an institution such as CWC or in a regional institution or in a community institution. Anyone who thinks these people can be put in what is now known as a "GROUP HOME" has not been exposed to their needs and the conditions existing in most group homes.

Philip must have two people available on every shift to lift him. He is totally helpless. He must be strapped into a wheelchair which he is unable to move. The prognosis by experts who have examined him is that he does not have the judgment nor the visual acuity to use a mechanized chair. He has to be strapped on to a special toliet. If he is put into a regular bathtub it requires special equipment to lift him out. Those who care for him must know CPR and be able to use the Heimlick Maneuver because he has a tendency to choke on his food.

At age 70, I am not going to be around too much longer. Before I go I would like some assurance that he will not be neglected.

I hold no brief for CWC. In my estimation it has a number of deficiencies but it is better than anything we have in La Crosse. We have been visiting him every other week for the past 15 years. We would welcome having him closer than Madison but we want what is best for him. His welfare is our major concern.

The best that La Crosse has to offer is inadequate for him and could easily become a fire trap since he is unable to move himself.

I think I speak for a great number of those in that 3% of the retarded when I say, . . . if you are so concerned about the amount of money being spent on these people that you refuse to provide them adequate care, then include in your bill an amendment to put them to sleep painlessly and permanently.

Respectfully,

Frank & Rita Pryor

Frank and Rita Pryor

P.S. We sent the enclosed letter to Senator Chafee. To date we have not received a response from him.

244 E. Pulaski St.
Pulaski, Wisconsin 54162
August 22, 1984.

Mr. Roderick DeArment, Chief Counsel and Staff Director
Committee on Finance
Room SD 219
United States Senate
Washington, DC 20510

Dear Mr. DeArment:

I am again writing in regard to bill S-2053, "Community and Family Living Amendments Act of 1983"

This bill would affect our son, Thomas Peplinski, 30 years old. Upon the advice of many doctors he has been a resident of Southern Wisconsin Center for the Developmentally Disabled, Union Grove, WI, for 26 years.

He is diagnosed as having tuberous sclerosis and as a result is a severe seizure patient as well as a behavioral problem. Each year at the staffing it is recommended that he stay at the state center because of his need for special medical treatment available only there. This is a Seizure Clinic. He cannot get better. His condition deteriorates as he grows older. His medication must be constant ly readjusted. He does not adjust to changes in his routine.

We know that our son and others like him are a minority, but this minority definitely needs the specialized care of a large center. Tom's medical treatment and care would not be available in a community home. We feel very strongly about the need for continuation of the program as Wisconsin has it set up at present.

Therefore, we ask you to OPPOSE THE PASSAGE OF THE PROVISIONS OF THIS BILL WHICH WOULD PROHIBIT THE USE OF MEDICAID FUNDS FOR PEOPLE IN INSTITUTIONS. If medicaid funds are taken away from institutions, the institutions will eventually have to close, no matter how well they are run and how satisfied their clients are.

Today, only the severely handicapped are in our state institutions. To disperse them to community living centers would take away their needed care for each community could not possibly duplicate the state center facilities. We know it would be easy to shunt them away and forget them... Our local County Executive is a low tax man and hardly im plements state standards for the handicapped. Besides "good" neighborhoods do not want community living centers because the value of their property would go down.

These patients do not adjust to changes. To have to drive them periodically to a city center for evaluation, treatment, etc. would negate any planned help. We know, we have been through it.

The social worker from our County Mental Health Board attended Tom's last staffing in May 1984. He could see that Tom would not fit in a community group home. We know that there are many more like our son.

We beg you to give our son and others like him your greatest consideration.

Sincerely yours, Norbert and Dorothy Peplinski

Norbert and Dorothy Peplinski

August 27, 1984

Mr. Roderick DeArment
Chief of Counsel & Staff Director
Committe on Finance
United States Senate
Room SD 219
Washington, D. C. 20510

Re: Senate Bill #2053
"Community & Family Living
Amendments of 1983"

Dear Mr. DeArment:

I am greatly opposed of the possibility of Central Wisconsin Center for the Developmentally Disabled and all other State Institutions Medicaid Funds being withdrawn.

This bill states that all retarded persons, no matter how severe their handicap, must live in the community in small group homes, and that no person, no matter how severe the handicap, may reside in a institution longer than a total of two years in his/her lifetime.

I would like to tell you a little about my child. David requires total skilled nursing care on a twenty-four hour basis. He is profoundly mentally retarded and has multiple congenital anomalies all due to mosaic-translocation of chromosome #6. He has severe regurgitation problems due to a massive gastroesophageal reflux. On March 10, 1982, a feeding gastrostomy was performed at University of Wisconsin Hospital. David receives all his food through the gastrostomy tube, although he continues to have occasional vomiting after meals. Physical and occupational therapy is performed on an irregular basis. Orthopedic consultation has revealed dislocation of the left hip secondary to muscle spasticity. On January 25, 1983, he had orthopedic surgery on both hip muscles and their nerves to reduce spasticity. Additional left hip surgery is required in the near future.

David has no self-care skills whatsoever despite his age of 4-1/2 years. He is non-ambulent,and will continue to require continuous skilled nursing care and daily observation by a physician, usually a pediatrician.

David will continue to require a high level of medical-nursing-ancillary care such as is provided in an acute pediatric hospital setting, such as Central Wisconsin Center.

David could not and probably would not survive comfortably in a small group home, where what is now being provided for him, could not be provided in a small group home.

I personally feel that if this bill were to pass many families would be torn apart, and most of all the retarded citizens in this state, already struggling in their lives would be at a loss with no where to go, and no one to help.

As of now, we are not receiving any State or Federal assistance in the care of our son, our insurance company has paid 100 percent. But for those who aren't as fortunate, this letter is for them. These retarded citizens and their families need your assistance. Please I urge you to cancel this bill and continue to help those who cannot help themselves. These people need your assistance.

It was not an easy decision to make when placing my child, but for him it was the best thing possible, he is not pressured and is at home in a very home like atmosphere. I visit him regularly. I have not and will not ever give him up.

I want the best for my child, and Central Wisconsin Center is the best for him, with very loving, caring, sympathetic staff.

Please visit some of our State Institutions, and you will see that what is being proposed would be impossible for many residents.

Thank you for your time and consideration.

Sincerely,

Mrs. David A. Putz

Mrs. David A. Putz
3622 Carter Street
Racine, WI 53402

4607 Wallace Ave.
Monona, WIsconsin

August 14, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Washington, DC 20510

Dear Mr. DeArment:

We are writing this letter in opposition to Bill S-2053, "Community and Family Living Amendments Act", which is being considered by the Senate Finance Committee's Sub-Committee on Health, chaired by Sen. David Durenberger of Minnesota.

One of the objectives of the bill would be to withhold federal funds from state institutions charged with the care of retarded people who don't qualify for placement in group homes or certified nursing homes. If this bill were passed, it would endanger the health, and in some cases, the very lives of retarded people now living in these institutions.

Our interest in this legislation is that our daughter, Rita Rank, is a resident at Southern Wisconsin Center, Union Grove, Wisconsin. She has been there for 21 years. We kept her at home until age 15, at which time Mrs. Rank's health broke down and other arrangements had to be made. Rita has the dual handicap of severe retardation, mental age 18 months, and total blindness. Prior to her placement at Southern Wisconsin Center, we looked at alternate facilities, but none existed. In 1972, there was pressure put on us to move Rita to a certified nursing home, and as these homes were located for us that would accept Rita, we visited those and evaluated them, using Southern Wisconsin Center as the facility to compare. Using "100" as the rating, we gave Rita's present domocile, the highest rating we could give any of the suggested placements was a "5". As time went on, most of the places suggested were decertified because they were fire traps, filthy, and had no programs to improve the abilities of the retarded. In 1977, the social worker who had the job of finding a different facility for Rita, wrote us and stated that because of her dual handicap, the only place capable of caring for her was Southern Wisconsin Center, and that until some facility, which would be equal or superior to Southern Wisconsin Center was found or built, that she should remain there. Our high regard for Southern Wisconsin Center is based on 21 years of watching how this institution cares for Rita, and that high standards exist and trained personnel staffed the facility. A table or organization exists so that everyone working here is observed in the performance of their duties.

Any action taken to close down the State of Wisconsin Institutions for the care of retarded people would be to deny these people their equal rights under the LAWS OF MAN and under the LAWS OF GOD.

Sincerely,
Mr. & Mrs. Fred Rank
Mr. & Mrs. Fred Rank

Aug 27, 1984

Dear Mr. DeArment:

I am writing in regards to bill # S.2053, "Community & Family Living Amendments of 1983"

I am the mother of a 14 year old severely retarded girl. She has partially impaired vision, almost total hearing loss even with an aid, can walk only a few steps and cannot speak at all.

My husband and I kept our daughter at home for 4 years before the emotional and physical stress became overwhelming. We then opted for foster home care before institutionalization, but although the foster parents were wonderful people it did not work out. She then went to Marshfield Clinic for a work-up and was transferred to Central Wisconsin Center at Madison, Wisconsin.

I have some serious reservations about this bill that concern my daughter and others like her. I feel that in a group home "Kristy" would be subjected to a much greater amount of physical danger — stairs - electrical outlets stove etc. that is not present in the Center where she now resides. She does not seem to learn from a painful experience as normal children do, in fact, she fails to feel pain to some extent. A severely retarded youngster is not easily taught the meaning of "no" and cannot grasp the concept of "danger," "harm" or "bad".

Those who are in favor of the bill, I would guess, believe that a group home setting would provide continuity in personal relationships. I don't believe this. At the Center, Kristy has relationships with and relies on a variety of people. If one or several leave the center she always has others she knows and can rely on. In a group home she would rely more intensely on far fewer people, and it would be more traumatic for her to lose them. I have seen one set of foster parents unable to cope with Kristy and 3 other prospective ones backed out of foster home arrangements because different "things came up." (legitimate reasons). I have seen how easily things can change when only a few people are or would be involved in Kristy's care. I do not want my child shifted from place to place.

The gains Kristy has made (and it really has been nothing short of remarkable) have been made painstakingly slowly and with the co-operation and back up of all Center staff. I fear that in a group home setting, with only a few people caring for these children who need a tremendous amount of attention, that there would be backsliding. Something may be lost in a few weeks time that may have taken years to teach.

I do not want my child residing with those individuals physically capable of causing her harm or vice versa. If all those of a certain ability are grouped together. (I am speaking of the severely retarded) then certain environmental and care criteria need to be set up - wouldn't this just be institutionalization on a smaller scale?

What about the inspection of this multitude of group homes as far as safety, care and quality of staff? More people would be needed for group home parents and it takes very special, motivated, dedicated, professionally trained ones for this job. Where are they to be found? What about neighborhood prejudice that could jeopardize my daughter's safety? I could write volumes about my objection to the passing of this bill where it concerns the severely retarded and in particular my own daughter.

I love my child very much and it grieves me that I cannot care for her myself or that there is not an institution close by where I could visit her more frequently, take her home or on family outings. I do, however, feel that Wisconsin's "Centers" for the retarded provide excellent care, training, stimulation, community outings, and even love for their charges. I feel it is the best possible environment for the severely retarded whose needs and training must be met on a continual and consistent basis.

I feel that bill #S.2053 will not work to the advantage of these seriously disabled youngsters - and could even be disastrous. I am adamantly against it and urge you to reconsider.

Sincerely Yours,

Sharron Rasmussen
2033 Severson Street
Eau Claire Wisconsin 54703

Aug. 13 - 1984

Dear Mr DeArment

My son resides at Southern Center, Union Grove Wi, and has been a resident there since Feb. 14, 1942. He is severly handicapped from birth. He is blind, severly mentally retarded, & has Cerebral Palsy. I do not even take him home on visits because he cannot tolerate any changes in environment or routine. He was put there by court order. He receives training & schooling by trained personel. He would never receive this kind of help & care anyplace else. When his teacher left the center, he was in such a turmoil he could not even go on field trips or any outings. He cannot after all these years of special care & training be put in a group home just to exist. The staff in these institutions are highly skilled in the care & needs of these children. As a mother my son does not even adjust to my visits, as he is a child of routine, & they have patterned him to a life style best for him. They have constant medical supervision & even a hospital on the grounds. An outsider wouldn't even know if he were ill. What a horrible thing to do to these children or adult children.

A Group home would not be safe or healthy let alone human, to put these people in the hands of unskilled personel.

How would the parents have any peace of mind with such changes. "Is this still America We Live In?"

These are God's children.

Sincerely

Diane S. Ratajczyk

N95W18147 Appleton Ave

Menomonee Falls, Wi

53051

mother of Duane Kraemer

Southern Wi Center - Union Grove Wi

August 14, 1984

R

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD219
Washington, D.C. 20510

Dear Mr. DeArment:

This letter concerns Bill S2053, "Community and Family Living Amendments of 1983". I do not wish to have this bill passed in Congress.

Twenty-three years ago my daughter was admitted by the Director of Southern Wisconsin Center. Before she could be admitted into this Center she was examined by two court-appointed pediatricians, a court appointed lawyer who saw her in our home situation, and a judge, who also visited her in our home.

It was agreed by all of these men that she should receive a court approval to be admitted for care at the Center.

She is a victim of cerebral palsy. She cannot roll over, crawl, sit, stand, walk or talk. Her motor nerves are severely damaged. The reason we gave her up at the age of three was because when one of the other of our four children would contract a cold, she would come down with bronchial pneumonia. Her life was constantly in danger. She has been in good care at the Center. "Community and Family Living" would put her in serious danger.

Bill S2053 may be suitable for some patients, but what possible plans are being made for the many patients such as our daughter?

At the Center she is taken to class everyday in her specially constructed chair. She receives special attention from those trained to do so. But her temperature is monitored around the clock -- they are always watching for infection.

Please take this into consideration and know that there are others who have this deep concern for their children as I do.

Again, I want you to know I am against the passage of Bill S2053.

Sincerely,

Mrs. Dorothy A. Reamer
1315 - East Elmdale Court #302
Shorewood, Wisconsin 53211

R

To: Mr DeArment,

I'm writing to you in regards to a bill - S. 2053 titled, "Community & Family Living Amendments of 1983." This bill if passed, would result in my daughter not receiving the total care and close medical supervision that is currently being provided to her at Southern Wisconsin Center for the Devolopmentally Disabled.

My daughter, Sheila Richard, is 23 years old and her overall functioning level has regressed during the past year. Sheila's last psychological test revealed scores of S.A: 05; S.Q.: 02, which indicates profound retardation. She has to be kept in diapers and fed by someone. Sheila is unable to fulfill even her most basic needs for herself.

This bill, by not holding any exclusions for chronic patients, holds the naive notion that all psychiatric illness is currently treatable to the point of remission and social adaptiveness to community centers. Our legislators need to stop the dismantling of state hospitals untill they can at least establish some priorities so as to save the most crucial elements of services to be rendered. Of top priority should be the state hospitals that provide chronic care facilities for those patients unresponsive to current treatment. It's this essential service of society that the state hospital give, and the private sector is totally incapable of giving. Deinstitutionalization has already been a disaster in communities in Massachusetts. This bill S. 2053 is a simple solution for deinstitutionalization. America has already found out that in changing our social welfare systems, simple solutions are usually wrong.

Sincerely,
Ms. Rachel Richard

Betty J. Robertson
Rt 2 Box 38
Eagle, Wisconsin
53119

August 17, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

Regarding: S.2053 "Community & Family Living Amendments of 1983"

Dear Mr. DeArment,

My twenty-two year old daughter is presently interned at the Southern Wisconsin Center for the Developmentaly Disabled (SWC). She is suffering from Downs Syndrome, severe brain damage and Grand Mauls Epilepsy. She has been evaluated to have a mentality of an eighteen month old child. In addition, she also requires special, twenty-four hour, attention to guard against her epileptic seizures.

A community atmosphere would not be of any benefit to a person that is oblivious to that concept. My daughter's condition is not one that would be improved by exposing her to community life. In fact, by moving her to a new facility you would be negating all the progress that she has made over the past fifteen years. It is my fear that a "Community Atmosphere" would only tend to ostracize her even further. It would expose her to the generally misconceived ideas about retardation that are prevalant throughout our society and make her the object of cruel and possibly malicious humor.

With the gradual removal of Medicade funding, the burden of these expences would slowly fall to the community. This could be a source of resentment that could seriously affect the quality of treatment that my daughter recieves.

Unfortunatly, my daughter will never be well enough to recieve any rehabilitative benefit from a community "group home" setting. She needs the care and attention, along with the security that only an institution like Southern Wisconsin Center (SWC) can provide.

In view of these facts, I must inform you that I am strongly opposed to this legislation (S.2053). It can only increase the hardships already faced by my daughter and intensify the anxiety felt by myself and other parents in my situation.

Thank You Very Much
Sincerly,

Betty J. Robertson

Betty J. Robertson

R

Dear Sirs

Re: Bill # S-2053 - "Community and Family Living Amendment Act"

My Son Dennis Rauch is a non-ambulatory 25 yr old male, severally retarded and epileptic. Dennis has been a resident of Southern Wis. Colony for some time now, his adjustment period after first placing him was very difficult for him and us, but he is now very well adjusted and happy at Southern Wis. Colony.. his "home." He is totally incapable of living in a community group home, as he cannot dress, undress or take care of his personal needs.

I feel this bill is very extreme, why is it we always cut expenses in areas that hurt either the old people or those who can not take care of themselves, such as the retarded! We are always helping adults & children in foreign countries to survive, with food, clothing and medical attention. What about our poor children who cannot think or do for themselves. I'm afraid my son would not survive in a community group home with all of his problems!

Southern Wis. Colony has to be kept open for all of those who would not make it in a community group home. Perhaps a visit to Southern Colony would be in order, to see how happy these children are, please do not displace them!

Sincerely,
Richard & Donna Rauch

5528 12th Ave. South
Minneapolis, Minn. 55417
August 23, 1984

Roderick A. De Arment, chief counsel
Committee on Finance
Washington, D.C. 20510

Dear Mr. De Arment,

We are writing you concerning S.R. 2053, a bill relating to the community and family living amendment of 1983. We understand that if passed this bill would, over a period of time, phase out federal medicaid funding to facilities serving more than 9 mentally retarded residents.

Our son Eric is profoundly retarded with cerebral palsey. At age 18 he is confined to a wheel chair and totally dependent on others for his care. He requires an adult to dress him, change him, bathe and feed him and to administer medications several times each day. It would be an extreem hardship for us to have Eric home with as and even if we did we would need help in caring for him. Our son is currently a resident in a small group home containing 63 children, divided into four separate living units. He has adequate staff and good medical and nutritional care in this kind of a non-profit home dedicated to the care of mentally retarded and handicapped people. In another city our son was a resident of a very large state institution and we much prefer the group home where he is, Homeward Bound, of New Hope, Minnesota. Federal medicaid funding enables excellent facilities like Homeward Bound to continue and we are now waiting eagerly in hopes that our son will be accepted in the adult facility of Homeward Bound in Brooklyn Park, Minnesota. We are afraid that the confinements like the limit of 9 residents would close or drasticly alter the kind of facility we seek for our son. He profits greatly from the size of the staff and the stimulation of the extra programming enabled by the larger group home.

We clearly recognize the fact that for many retarded or disabled individuals a smaller unit of 9 or less persons may be even more ideal. What we want is to maintain more choices or options for families to consider. Some people may still prefer the large state institutions, however we think this option should be greatly limited. More and more parents should be given the financial, educational and emotional support they need to keep their child in their own home, (an option not available to us 15 years ago).

We also can see the exciting possibilites of integrating disabled persons with more normally functioning communities to share the tasks of living. These group homes or "communities" may be the least expensive option for our federal medicaid funds if we creatively tap the abundant human love and volunteer spirit available in America. We dare not limit such options to only groups of 9 or less.

We in the state of Minnesota are proud of the variety of fine options we have for the care of the mentally retarded. We want to maintain this variety in Minnesota and to encourage it in other states without unnecessary federal limitations.

If a common concern we all have is to keep expenditures within fiscally responsible limits then we suggest that the government encourage even more imput and control of facilities for the disabled by parents and local community leaders. We must trust the wisdom of those persons closest to the need to make proposals and policies that use to best advantage the dollars available. In so doing, we may be able to avoid the tragedies and waste of some large istitutions and small profit oriented residences that lost sight of the individual human worth and care needs of people.

In conclusion, let us summarize by stating that we are opposed to the bill sponsored by Senator Chaffee, S.R. 2053 as authored by the National Association for Retarded Citizens. We like the direction of moving toward smaller living units and yet we oppose federal standards that limit options and that would probably cause our own son to lose a great care facility he needs.

Sincerely,

Donald Rudrud Karen Rudrud

Donald Rudrud and Karen Rudrud

copy to Senator David Durenberger
U.S. Senate, Washington, D.C. 20510

Testimony to the U.S. Senate Finance Committee Subcommittee on Health

Re: Subcommittee Hearing on S 2053, "Community and Family Living Amendments Act"

Hearing Date: August 13, 1984

Hearing Site: Minneapolis, Minnesota

Submitted by James L. Sankovitz
4057 North Prospect Avenue
Shorewood, WI 53211

Mr. Chairman and Members of the Subcommittee:

My name is James L. Sankovitz. I am Vice President for Governmental Relations at Marquette University, Milwaukee, Wisconsin.

I write to you about the long-range implications of S 2053, The Community and Family Living Amendments Act.

My interest in this proposed legislation derives from the living circumstances of an older brother, Thomas, a Down's Syndrome handicapped citizen who has lived for fifty years at the St. Coletta School (Alverno Cottages), in Jefferson, Wisconsin.

The thrust of S 2053 is to modify Medicaid payment delivery so that a deinstitutionalized distribution of the mentally retarded and developmentally disabled population would result in ten to fifteen years from enactment.

My view is that, while deinstitutionalization may be appropriate for many such citizens, a rigid stance is not appropriate. There are some such victims who have adjusted to institutional life with great affection. At the same time, many of them rely at least partially upon the current status of Medicaid funding for the subsistence delivered by the institution.

For those proponents of the Act who dismiss the importance of this segment of the affected population by stressing the ten to fifteen years phase-in component of the proposed legislation, I believe they are attempting to fix a universal standard for a population which cannot be treated universally.

Community-based locations in small groups may be appropriate for some (perhaps the majority) but not all, particularly those who have already established a familiarity with major, proper institutional settings. For this population alone, a ten to fifteen year period is insufficient. Given the absence of stress and tension and the presence of skilled, caring professional experts, many such handicapped citizens could outlive this artificial deadline by a substantial period of time. Legislation ought to recognize that probability.

I respect a great deal the genuine and able services delivered by the many health care personnel who serve not only the needs of large institutions but the community-based enterprises as well. Their ambitions and skills are gaining widespread recognition and the good of their accomplishments is obvious. In this respect, I have watched the development of the new Community of the Ark in Washington, DC, a community-based location now serving four residents of that city. I wish them success in expanding their good works.

At the same time, however, it would be prudent and reasonable to amend the proposed legislation to permit continuing institutional life style for those citizens who have either become dependent upon such a setting or for those in the future who opt for the same opportunity. Medicaid opportunity, too, ought to prevail for these people.

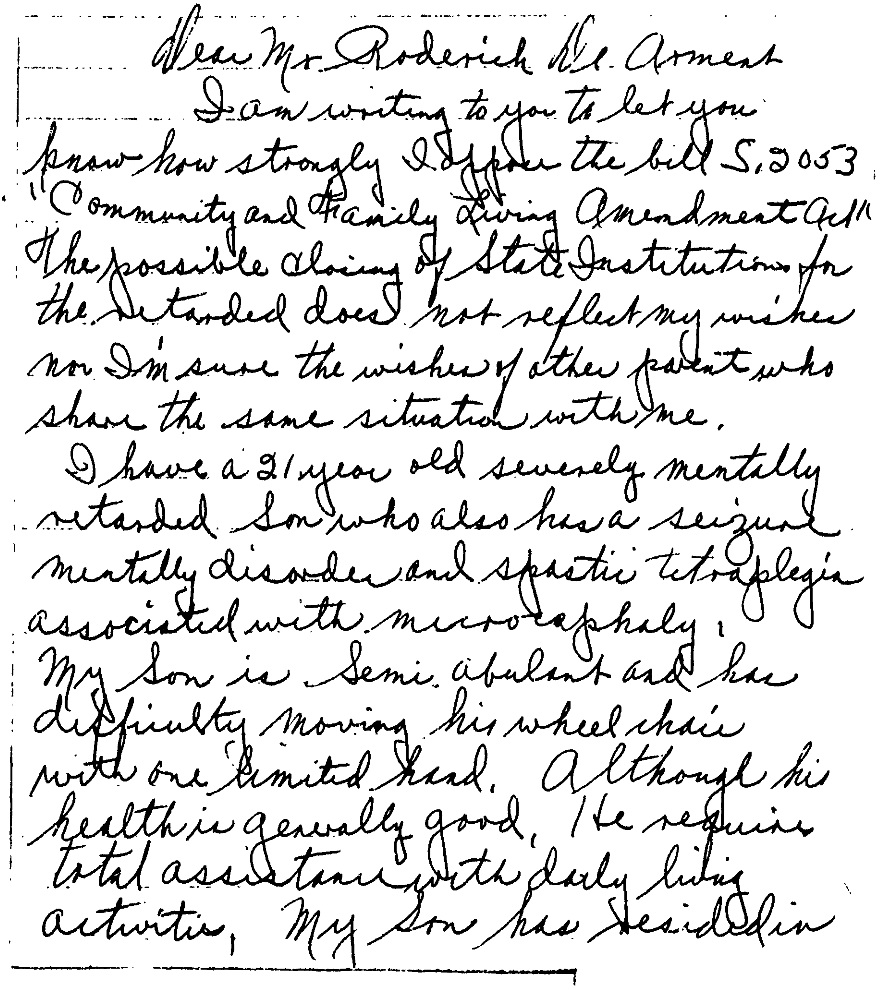
Your willingness to hear the views of the general public on this matter is appreciated. It provides hope that in the necessary work of reevaluating Medicaid, damage that no one would cause intentially will not be caused by inadvertence. Thank you.

Dear Mr Roderick De Arment

Please consider this letter as Written Testimony for the hearing on S. 2053 which was held in Minneapolis August 13 1984 by Senator Durenberger.

Thank You so much.

Sincerely
Mr & Mrs Melvin Schmitz
185 E Arndt St.
Fond du Lac
54935 Wisc



Dear Mr Roderick De Arment

I am writing to you to let you know how strongly I oppose the bill S.2053 "Community and Family Living Amendment Act" The possible closing of State Institutions for the Retarded does not reflect my wishes nor I'm sure the wishes of other parent who share the same situation with me.

I have a 21 year old severely mentally retarded Son who also has a seizure mentally disorder and spastic tetraplegia associated with microcephaly. My Son is Semi abulant and has difficulty moving his wheel chair with one limited hand. Although his health is generally good, He requires total assistance with daily living activities, My Son has resided in

Central Wisc Since 1967, With the perceived needs that my Son has I feel that the closing the institution is definitly a lost to him, There is no way my child could receive the care he needs in group homes with no medical facilities near by. He has been given a lot of love and nothing but the best of care while living there. With the closing of the Institution you will be taking away something that is so important to him, I am seriously asking you to reconsider your feeling about this bill.

Please remember it is our special kids that are going to be hurt and hurt dearly

Sincerely

Mr + Mrs Melvin Schmitz

Aug , 1984

To whom it may concern, Mr Roderick De Arment,

Reference: Bill # S 2053
Title "Community & Family Living Ammendments Act."

This is in reference to closing of state institutions for the retarded.

It would be a great hardship for our son as he has been there for 31 years and definitly cannot cope with the outside world.

Our state evaluation papers state that he cannot take care of himself, so he could not go into a community living arrangement or group home. He cannot even cope with coming home for a vacation or holidays. Every degree of achievement he has acquired has been with the help of those at Union Grove. His diagnosis is: profound mental retardation associated with HYPERBILIUBRUBINEMIA, non verbal but ambulatory.

We think that a bill like this is really unfair as we and he have had to live with this all his 38 years. If he was taken out of Southern Colony he would be dead in a short time.

We also feel that group homes would be more costly as these facilities, they are now in, are already established. This idea of group homes is unthinkable. How could anyone have the heart to uproot these unfortunate human beings after they are so accustomed to the quarters where they now live.

As we said before this idea is unfeeling and unthinkable.

Sincerely,

Patricia Schneider
Carlos H Schneider
N75 W15472 Colony Rd
Menomonee Falls Wi
53051

Aug. 13, 1984

S

Mr. Roderick De Arment
Chief Counsel & Staff Director
Committee on Finance
U.S. Senate
Room SD 219
Washington, D.C. 20510

Dear Mr. De Arment:

We are writing regarding a bill, S. 2053, which was presented by Senator John Chafee, Rhode Island, Nov. 7, 1983. It is called the "Community & Family Living Amendments" of 1983 & is being studied by the Senate Finance Committee's Subcommittee on Health, and chaired by Senator Durenberger. We are very much concerned about this matter, for we have a son staying at the Central Wisconsin Center at Madison, WI and due to his condition, because he is so severely retarded, we don't know how he could possibly be taken care of in our community nursing home here. There is not a facility available here in Antigo that could take care of our David, for he is totally dependent on someone's care and needs special thereapy and attention. We find the Wisconsin institution a very acceptable and proven alternative to the proposed community placement. They give him such proper care and thereapy at the Central Center and we don't know where he would receive this kind of care.

We are strongly against bill S. 2053 and certainly hope the proposals of this bill will not happen.

Thank you for your attention on the above matter.

Concerned Parents,
Mr. & Mrs. Don Schroeder
N 4050 - Hwy. 52
Antigo, WI 54409

Aug 10, 1984.

In re: Bill # S-2053
TITLE "Community & Family Living Amendmants of 1983

My son would not be able to adapt to community living. It has been tried & failed. He would end up in jail - he has broken into neighbors homes & stolen money. The courts would send him right back because of his past record. He is now 31 yrs. old.

I cannot handle him alone. I am 58 yrs old - single & still work full time. Please do not help to pass this funding bill. I am strongly against this bill. It is very reassuring to know that my son is with his own kind - & does not have to 'compete' with the outside world.

Thank you
Mrs Dorothy Schultz
2005 Norton Ave
Waukesha, Wis. 53186

P.S. My son is at Southern Wis. Center at Union Grove, Wis.

S

The James Senger Family
141 E. Prospect St.
Port Washington, Wis. 53074

Mr. Roderick De Arment

Concerning Bill # S.2053 - Community and Family Living Amendments of 1983

I beg you to please take the time to read my letter. It is written on behalf of my son Tom, who lives at Southern Wisconsin Center for the Developmentally Disabled. Tom is a 23 yr. old profoundly retarded child. He cannot speak, dress himself, toilet train, or communicate any of his wants or ills to anyone. He has no idea that things such as cars, butcher knives, hot stove burners, etc., will harm him. When he was eight years old, we realized that we could no longer physically protect him from the dangers that exist in a normal home and with much soul searching and prayer we decided to place him at the Southern Wisconsin Center. This was the hardest thing we have ever had to do but it was for his benefit, not ours. We are sad but not sorry because we know he is safe and well taken care of.

This bill will destroy the protected environment that thousands of Toms now have. Money is poured out to protect endangered animal species without a second thought, please give these special children the same chance. I invite your to tour our Center at Union Grove, Wisconsin and see the wonderful things that are being done there for these children, things that could not be done in group homes or community living arrangements. They do everything they can to try and return these special people to a home environment, but there are thousands of these who cannot possibly exist in a normal home life and if this bill passes, there will be thousands of parents who will never again have a peaceful nights sleep.

Please give these children a chance, don't let them be returned to the times when they were forgotten. Spend just one day working at one of these special places and you will see that these places cannot be closed. For the sake of all the Toms in this world, do not pass this bill.

Thank you for your time and consideration on this matter.

THE LOVING PARENTS OF TOM SENGER

Mr. & Mrs. James Senger

5

146 Harrison Avenue
Waukesha, Wisconsin 53186
August 28, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room Sd 219
Washington, D. C. 20510

Dear Mr. DeArment:

Re: Bill S. 2053
"Community & Family Living
Amendments of 1983"

This Bill would force our son age 26 years into a living situation he could not tolerate and where restraints would be necessary for his protection. It would rob him of the limited freedom he now enjoys. Community placement would be "slamming the door in his face".

Our son is severly handicapped, both mentally and physically. He was placed in the institutions at the age of 3 years and we observed him progress from the use of initial restraints to the unrestrained, supervised environment he now enjoys. He is not able to walk or talk, but enjoys crawling about the large area he is presently in. He can pull himself up to reach for things which attract him. (Could a small group home allow this freedom?) He does not relate well to his peers and occasionally gets extremely upset and self-abusive; the patience and perserverance of staff aides at Central Wisconsin Center in Madison, Wis. have helped control these outburst without medication and only very temporary use of restraints. He also has occasional outbursts at nite and is able to be moved to an area where he cannot disrupt the sleep of other residents. Moving to a small group home would necessitate the use of medications and restraints that we do not approve of.

We strongly oppose Bill S.2053. It is totally without foresight. Why do you feel you can decide what is best for our child? He needs the freedom only the institutional setting can provide.

Bill S.2053 is a "kick in the stomach" to parents and disabled people. I have met and known some of the people in our area who have been hired to care for nursing home patients and the elderly. Too many of them are unqualified for any other type of work because they are incompetent. (I know these facts to be true from personal experience). They are offered these jobs to keep them off of welfare and they have no previous experience or training.

Please leave the system as it is. Don't allow our children to be victims of abuse and neglect.

Respectfully,

Mrs. Lee Shackelton

(Mrs.) Lee Shackelton

S

Watertown, Wi.
8/10/84

RE. Opposed to, Bill # S 2053
Community & Family Living Amendments.
of 1983.

I have a retarded son who has been a resident of a State Institution for the past 18 years. He is profoundly retarded, has seizures, is unable to speak and can not function normally on his own. Being placed in a Group Home would make it impossible for him to survive without the constant medical and nursing care.

The State Institutions are a safe and comfortable environment that means home to thousands of children and adults. They provide a specialized and caring home-like atmosphere for each resident.

I personally feel, if this bill would be passed it would be unfair to the thousands of people who have retarded children. Some of us are at Retirement age and would be unable to cope without the Institutions, physically, mentally, and financially

I am strongly against this bill as the best and healthiest place for my son and all the other retarded Citizens across the country, are the State Institutions

Sincerely,

Gloria Shaikin

S

1606 North 29th Street
Sheboygan, WI 53081
August 28, 1984

The Honorable John Chafee
United States Senate
567 Dirksen Senate Office Building
Washington, D.C. 20510

Sir:

I am writing to express my strong opposition to S.2053, Community and Family Living Amendments 1983. I am a parent of a five year old child who has been placed at Wisconsin's Central Wisconsin Center for the Developmentally Disabled in Madison, Wisconsin. Laura was born "under trauma" and premature, resulting in a variety of medical difficulties. The majority of her first year was spent at the Milwaukee County Hospital's Neonatal Intensive Care Unit and Milwaukee's Children's Hospital. For about nine months, following that first year, she lived at home. Her medical needs continued to be extraordinary and frequently exceeded the medical expertise of our community. Laura endured many encounters with local physicians and recurring trips to Milwaukee Children's Hospital.

Laura is a living example of what can go wrong despite/because of the heroic efforts of physicians and medical technology. Her overall physical and mental development in all areas, as determined by a variety of measures, is that of a child of three months or less. Because of ongoing seizure activity, no conclusive measure of sight or hearing can be completed. She has no head control. Locomotion is limited to a stomach-to-back roll. Her most consistent response is a telling smile during any physical human contact.

Laura's developmental needs far exceed those of most children. During the time Laura lived at home, the Sheboygan County Rehabilitation Center sent a visiting therapist to our home two to three times a week for 30-45 minute sessions. The services Laura receives at Wisconsin's Central Center far exceed those available in our community. This is possible because of efficiencies of scale. The Center's population includes sufficient persons in each of a variety of need areas to justify the employment of trained professionals who collectively can address each child's special needs.

The ongoing medical and developmental training needs of people like Laura cannot be met in small or medium size communities (Sheboygan - population 50,000). Attempts to place all persons with special needs, no matter how complex the individual's needs might be, in local community centers or outpatient care will likely result in one or more of the following:

- increased overall costs because of duplications in services caused by each community striving to meet diverse needs with small populations in each need "category"

- severe cutbacks in services to people with complex needs or rare disabilities because of the high cost of providing specialized services to a few people

- the availability of services will depend on one's location; the larger the local population, the broader the range of available services

- localities with limited resources will provide merely custodial care for persons with long term disabling and/or complex needs.

My experience with Wisconsin's Central Center indicates that this facility offers a broad range of services for children with severe and profound handicaps and/or long term medically disabling conditions. I believe there will continue to be a need for residential facilities that can provide both developmental and medical care to people with complex special needs. Placement decisions cannot rest solely on the "least restrictive environment" test. Consideration must also be given to providing optimal opportunities for development, no matter how limited the potential may be. Both criteria must be considered to insure the <u>most appropriate placement</u> of handicapped persons.

We have all heard the horror stories surrounding mismanaged and understaffed institutions. Immediate action should be taken against those institutions which permit insensitive and unprofessional conduct. I obviously feel that the staff at Wisconsin's Central Center has demonstrated their ability and desire to provide high quality, individually appropriate services to their residents. Yet, S.2053 appears to castigate all non community based residential settings.

All families want healthy babies whose development they can nurture with joy. Unfortunately, some families must deal with children whose medical and developmental needs far exceed the resources of their family and the medical/developmental expertise of their communities. Our decision to place Laura outside of our home and community was most difficult. We gain solice from our belief that this placement has provided her the best care available, both for her medical and developmental needs.

Very truly yours,

Robert J. Snavely

Robert J. Snavely, Ph.D.

August 21, 1984

TO WHOM IT MAY CONCERN -

Re - S.2053
"Community & Family Living Amendments of 1983"

We are parents of a son, now age 20, who is a resident of our State institution at Madison, Wisconsin, and has been for almost seven years. We feel very strongly that with his handicap (a rare type of encephalitis with onset at age 12) that he is receiving the best possible care at Central Wisconsin Center, along many others who are severely handicapped either through illness accident or since birth.

We ALSO feel that passage of the above-named bill would be detrimental to this segment of our population and, of course, OUR SON. Prior to his illness, we were not aware of the necessity for this type of institution--the needs of these people could DEFINITELY not be met in a community/home situation.

If you have any doubt about this, may be humbly request that you take time from your busy schedule to visit such a place.

Please, DON'T support Senate Bill 2053.

Thank you for your consideration.

Sincerely,

Ray & Melba Stampfl

Mr. and Mrs. Ray Stampfl

8/23/84

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

T Whom It May Concern:

I am writing in regard to Bill S.2053, the Community and Family Living Amendements of 1983.

I am strongly opposed to having this Bill passed. My brother is totally helpless, and completely dependent upon others to feed, bathe, clothe, and care for him. The care he is receving at Southern Center, a Wisconsin institution, is very suitable for him and very acceptable to me. My brother is severely handicapped, and has no understanding of family living, so a group home would not be beneficial to him.

I would like to repeat that I feel my brother is an individual who needs the institutional setting, and that I am strongly opposed to the passage of Bill S.2053.

Sincerely,

Theresa Stapenek

Theresa Stapenek
Legal Guardian of
Thomas A. Drezek

Menomonee Falls, WI
August 18, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

RE: Bill S-2053 - Community & Family Living
Amendments of 1983

Dear Mr. DeArment:

We are writing with reference to the above mentioned bill regarding retarded persons, presented by Sen. John Chafee, Rd. Is., on 11-1-83.

We have a son who is severely retarded, unable to help himself. He is institutionalized at Southern Wisconsin Center For The Developmentally Disabled, Union Grove, WI, a very acceptable, proven alternative to community placement. It would be impossible for our son to live in a group home. He was placed in one for a while several years ago, but was unable to make the necessary adjustments and had to be returned to SWC.

We feel that Bill S-2053 is entirely unfair to the retarded and ask, therefore, that you please consider all the real facts and vote against it.

Yours truly

Mr + Mrs E. J. Streator

Mr. & Mrs. E. J. Streator
W160 N9013 Madison Avenue
Menomonee Falls, WI 53051

ms

Ruth St. Clair,
P.O. Box 145
Delavan, Wis. 53115.

Community of Family Living
Amendments Acts
No. of Bill - S - 2053.

Aug 15, 1984.

Mr. Roderick DeArment:

Why disturb helpless Children?
Their not able to help there selves. I'm
really Angry + disturbed about this bill, it
isn't fair to thoes Children. I'm strongly
opposed of such a bill and I will not Vote
to pass this bill on mediciad funds for the
retarded citizens of Southern, Wis. Center in
this institution.

I have a girl 37 year's old in
Southern Wis. Center. Union Grove, Wis. She
has been really a problem ever since she
was 10 months old, she had 107° degree
fever which damaged her brain thru
sickness. She has a longstanding history of
anemia, Varicose veins, ear problems, She
may yet even go deaf. Chronic recurrent in-
fections for years. She has many ailments.
She has a mind of a 3 to 5 year old. When
she gets upset she has the strength of 4 to 5
people put all to-gether. I dearly love her,
But I'm too old to have the constant care
she needs. She can be very aggressive and
self abusive at times.

Maybe you don't have a disabled
or mentally child of your own, They have feelings
just like you or I do. But if you do have
a child in that condition, You would think
twice before you passed a bill like this,

I) and to place a retarded child among strangers; it just wouldnt work with her. Theres no way my girl could receive better care than what shes getting there in Southern Colony, Union Grove, Wis.

Southern Colony has been a well established residence for year's for the mentally retarded + disabled children. They know what care each child needs, weather its medical or other needs, If they need help they get it. They all look after one another. Its like a family home.

The Doctors are there when ever they are in need. They have their medical supplys, food, Clothing, heat, and what ever the children need. I can truly say its a wonderful place for thoses children. What more could any one ask for. They even have their receation periods.

If my girl was moved to a group place, Among strangers she would be very upset. Right now she is content, + Satisfied, and has her friends to play with. I can get her home for a couple of days vacation and she really enjoys that. She's always happy to see her mother.

Thank You;
Very Truly Your's;
Mrs. Ruth St. Clair.

T

2411- So. 63 Street
West Allis Wis 53219
Aug. 15, 1984

Dear Mr. De Arment,

I strongly oppose the proposed "Bill S 2053 - Community and Family Living Amendments of 1983."

There are many children, including our granddaughter, who could not function in a group home.

Southern Wisconsin Center is a fine facility where they receive the care and personal attention they need to survive and survive happily.

Our granddaughter is retarded, has hearing, speech, sight and spine impairment and suffers seizures.

She needs constant supervision, physical and occupational therapy, teachers and medical attention at hand.

A changed environment would be detrimental to her and many of the children.

We, who have lived with this for many years, know what is best for our children and want to be heard.

Please listen.

Sincerely,

Mrs Beatrice Terch

August 16, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

Re: Bill S-2053 "Community & Family Living Amendments of 1983"

Dear Sir:

I am opposed to this bill because it will adversely affect the wonderful institutions for the mentally retarded that we have here in Wisconsin. Perhaps other states may need it but we certainly do not.

I have two friends with retarded children in two different facilities in the state and I cannot find words to describe the marvelous care these children receive. Neither of them could possibly live in a community situation.

Please consider the effect this bill would have on our great facilities and do not make a generalization that would destroy what is one of our greatest assets.

I do hope this will be considered written testimony for the hearing which was held in Minneapolis on August 13th, 1984 by Senator Durenberger.

Thank you for your consideration.

Erane R. Thomson

Erane R. Thomson
8700 N. Port Washington #212
Fox Point, Wi 53217

C. Jack Truckler
405 Fieldstone Drive
LaPorte, Indiana 46350

August 28, 1984

Mr. Roderick DeArment

Re S. 2053

Community + Family Living Amend. – 1983

As one who has lived with a mentally handicapped person for most of my adult life I feel the subject bill would be a serious error. It is beyond the capability of local, community efforts to provide necessary maintenance and care for all handicapped persons.

Truckler

TCSAC

TWIN CITIES SOCIETY FOR AUTISTIC CHILDREN, INC.
1729 Carroll Ave. • St. Paul, MN • 55104 • (612) 642-9042

Dedicated to the education, welfare and cure of children with severe disorders of communication and behavior.

August 29, 1984

Roderick A. DeArment
Chief Counsel
Committee on Finance
Washington, D.C. 20510

Re: Hearing on "Community and Family Living Amendments" bill, S.2053

Dear Mr. DeArment:

I am writing on behalf of the Board of Directors of the Twin Cities Society for Children and Adults with Autism, Inc. relative to the above referenced bill.

The Twin Cities Society for Children and Adults with Autism, Inc. (TCSAC) is a non-profit organization of parents and professionals advocating for children and adults with autism. We believe (1) that autistic and other disabled persons are entitled to a place within the structure of society and, to the extent possible, are entitled to participation in the same scope of experiences and opportunities as afforded non-handicapped persons; (2) that, in order to promote full participation in community and family living, a continuum of residential, educational and community services must be provided - whenever possible - in integrated settings with non-handicapped persons; and (3) that integration with non-handicapped persons enhances growth and development, and ultimately, the overall quality of life for disabled individuals.

TCSAC believes that through the availability of family and community-based services, many "at risk" individuals can avoid placement in Intermediate Care Facilities, and further, many individuals already placed in ICF's could function in less restrictive and more normalized settings. However, the current system of Medicaid funding provides states and counties with fiscal dis-incentives for providing community-based services, and as such, the proposed bill would remedy this skewed pattern of funding.

During the past two years, TCSAC has been advocating for appropriate placements for autistic adults. Based on reviews and assessments of ICF's in the Twin Cities metro area, our concensus is that both the level of care and the quality of living are infinitely greater in facilities of 6 to 10 residents. Accordingly, it is our contention that Medicaid funding should be withdrawn from large state or privately-owned institutions.

A Minnesota non-profit corporation • A chapter of the National Society for Autistic Children.

In summary, we believe that the paramount issue with regard to the Community and Family Living Amendments bill should be the quality of life for disabled individuals, and we strongly support this proposed legislation.

Thank you for your consideration of this matter.

Sincerely,

Renee Moen

Renee Moen
Legislative Affairs

RM:ls

August, 1984

We are writing as concerned parents regarding SB - 2053 "Community and Family Living Amendments of 1983".

We have a 4½ year old son who has been a resident of Central Wisconsin Center for the Developmentally Disabled for the past year. He is blind, profoundly retarded, microcephalic, severely involved with spastic cerebral palsy, and has an uncontrolled seizure disorder. At age 4½ he has the mental and physical abilities of a 2 month old baby. One year ago we voluntarily placed him in a residential setting because we firmly believed this would be for his best interest. We have not been wrong. For him this has meant a controlled environment which has been crucial to his fragile medical health. We chose residential placement because of the constant 24 hour care we could not continue to provide. He now has available to him services that are not available in the community for the profoundly handicapped.

By passage of SB - 2053, our son would be returned to the community to services which are not even available and therefore have not been proven to be better than institutional care at Central Wisconsin Center. From our understanding of this bill, all retarded persons must live in the community--not bearing in mind other profound medical problems which in all probability outweigh the mental retardation as a reason for institutional care.

We believe that if our son were only mentally retarded we would probably still be caring for him at home. No one can begin to understand the care involved in raising a profoundly disabled child unless they have had to provide that care. He requires diapering, being fed, frequent repositioning as he cannot sit up by himself or even hold up his head, exercising to prevent contractures, and stimulation. This is total care. Try to imagine care of a 2 month old baby in the body of a 4 year old. This is our son. This care requires a team approach and that's why we plan on having our child remain at Central Wisconsin Center for the Developmentally Disabled. We are strongly against SB - 2053 and its mandating that all retarded persons be placed in the community. We want to see Central Wisconsin Center and other institutions that provide exceptional care to the disabled remain open to us and other parents as an option in the care of our children. Our son would be done a grave disservice if he were removed from Central Wisconsin Center. Will the community group home be able to provide the medical care needed for a retarded child with a tracheostomy, or one who rapidly goes into respiratory distress, or who has a severe cardiac problem? We cannot envision our son being in a group home because the placement would be so inappropriate and detrimental to him.

Our son did not ask to be born brain damaged. He does deserve the best care available. For him that care will be in an institutional setting at Central Wisconsin Center. This is the best for him and it is working.

Thank you for your time,

Kevin & Rebecca Underwood

Kevin & Rebecca Underwood
4101 N. 69th St.
Milwaukee, Wisconsin 53216

V

United Cerebral Palsy - Northeastern Minnesota

105 Ordean Bldg. - 424 W. Superior St.
Duluth, Minnesota 55802
Telephone 726-4723

August 28, 1984

Mr. Rod DeArment, Chief Council
Senate Finance Committee
Dirksen Building
Room 219
Washington, DC 20510

Ladies and Gentlemen:

We are writing to express support for S.2053. If the community service and settings for severely disabled are to succeed, a secure, stable and adequate financing base for community services needs to be developed. This is why we support S.2053. We are not recommending 100% transfer of these medicaid funds from the state institutions. We do, however, favor a fair porportionate share equal to the populationship from state institutions to home communities.

The least restrictive environment should determine where an individual should be placed.

Federal, SSI eligible should be the initial targetted population to receive these benefits.

We express a wish for a successful passage of S.2053.

Cordially,

Mabel Schauland

Mabel Schauland, President-Elect

Helmi Lammi

Helmi Lammi, Executive Director

3002 So. 90th St
Milwaukee, Wi. 53227
Aug. 13. 1984

Mr. Roderick DeArment,
Chief Counsel and Staff Director
Committee on Finance
United States Senate
Room SD219
Washington, DC 20510

Dear Mr. DeArment,

I am strongly opposed to SB 2053.

Wisconsin has excellent State, County and Sectarian institutions for the profoundly mentally retarded residents. My daughter Phyllis, 42 years of age, has resided in one of these State institutions for 37 years and has received excellent care.

I do not wish to have her, and other severely handicapped persons, arbitrarily discharged into profit making facilities, because reports and my inspections prove they are very poorly operated.

If the helpless residents in these three excellent State institutions were transferred into profit making group homes the results would be Catastrophic!

I wish this letter to be used as written testimony for the hearing on S-2053 which was held in Minneapolis Aug. 13, 1984 by Senator Durenberger.

Yours truly
Philip H. Vaughan

cc - Senator William Proxmire
Senator Robert W. Kasten

V

VOICE OF THE RETARDED

798 LINDEN AVENUE
ELMHURST, IL 60126

Marty Pratt, *Chairman*
Phone: 358-6381
Jean Carlin, *Co-Chairman*
Phone: 474-4441
Bernadette Sullivan, *Secretary*
Phone: 834-2520
Liz Marguerite, *Treasurer*
Phone: 837-9481

August 1, 1984

Senator Dave Durenberger
U.S. Senate Committee on Finance
Sub-committee on Health
SD 219 Dirksen
Senate Office Building
Washington D. C. 20510

Dear Senator Durenberger:

It is with great duress we write you. Today we learned of the public hearing on Senate Bill 2053 on 8-13-84. Because of the shortness and impromptu timing of this meeting we will not be able to personally attend. If we follow the procedure set forth by your committee it would give us two days to prepare our testimony and have it arrive in Washington by August 3, 1984.

Therefore it is our urgent request that all future hearings be announced in ample time for people to prepare. It is also our request that a hearing be held in the Chicago-Metropolitan Area in September or October. We would like this letter to be included on the record as part of the August 13, 1984 Minneapolis,Minnesota hearings.

Sincerely,

Jean Carlin bs.

Jean Carlin, Co-chairperson
Voice of the Retarded

Copy: Senator Charles H. Percy
Senator Alan J. Dixon
Association for Retarded Citizens/U.S.
Senator John H. Chafee

RECEIVED
AUG 6 1984
CLEARBROOK CENTER

✓

Mr. Roderick DeArment

Ernest & Adeline Votava
Route 2 Box 245
Peshtigo, WI 54157

Bill # 2053
Title: Community and Family Living Amendments of 1983

We have a 24 year old daughter Kathy Votava living at the Central Wisconsin Center in Madison Wisconsin. She has lived at the Center for 19 years. She has been hopelessly handicapped and retarded since birth or shortly after. She has no use of her legs and limited use of her arms or hands At times she is self abusive but has improved thru the education and training she has received at Central Colony.

We go to visit her about 4 times a year (it is 200 miles each way) and is happy to see us there, but before long she is ready for us to leave and return to the enjoyable structured life she has come to so enjoy at Central Colony. These are people who constantly care for her and love her and the others who share her type of misfortune but even her handicaps do not dampen her spirits.

Do not misunderstand, we love Kathy as much if not more than anyone but both of us being in our 60's and not having the best health, we sincerely appreciate the environment Central Colony has provided. It is our hope and prayer they will be allowed to continue to provide for our dearest Kathy. We hope you share our concern for a part of our society that is unable to care for themselves.

Page 2

Please try to put yourself in the place of these poor misfortunate people. To shuttle them around now after the structured controlled environment they have experienced would be utterly traumatic. Even though in the long run, new misfortunate people would enter into the type of program you are sponsoring, we strongly feel those already in the current program structure should be allowed to stay.

Thank you for your time and your support in defeating or modifying this Bill.

Sincerely

Ernest & Adeline Votava
Route 2, Box 245
Peshtigo Wisconsin
54157

W

14 August 1984

Wayne M. Wagner
3233 West Grace Avenue
Mequon, Wisconsin 53097

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 10510

SUBJECT: Bill S. 2053
Community and Family Living Amendments of 1983

I am writing this letter to advise you of my opposition to passage of this bill because it will result in the closing of the Southern Wisconsin Center for the Developmentally Disabled in Union Grove, Wisconsin.

I am legal guardian for my brother Rickey who has been a resident of Southern Wisconsin Center for 17 years. Rickey is now 25 years old and prior to his admission was cared for by my parents who could no longer physically care for my brother. Rickey is non-ambulatory, nonverbal and his physical handicaps and level of retardation have prevented him from making any significant progress developmentally. He continues to be rather content but passive and quietly responsive to staff attention. He does become very agitated and screams when he is bathed, his diaper is changed, he is put to bed, etc. His only and favorite activity is watching television.

Rickey is receiving excellent care at the Southern Center and all of his needs are being met. The Southern Center has the staff and services available to meet his complete requirements; physical, mental, medical and dental. I do not see how any other facility could provide the same level of service that he needs and is receiving. There is no way that Rickey could contribute in any manner to a group home. He is completely dependent on others for his care.

My family and I are extremely happy with the service being performed at Southern Wisconsin Center. They are providing a service that can not be provided in any other way. Rickey is only one of many people who need these services. If there is ever a need for a government to provide a service I cannot think of any which would be more beneficial or is more badly needed. My brother cannot speak for himself, so we must stand up for his rights.

Please do not close the facilities that Rickey and others like him need.

Sincerely yours,

Wayne M. Wagner

Wayne M. Wagner

W

August 27, 1984

Dear Mr. Roderick,

I was driving along one of the streets at Southern Wisconsin Center for the Developmentally Disabled the other day. It was a beautiful, sunny day and I observed many of the residents.

Some of the people were walking, some were using the fenced play areas, and a small group was on the baseball diamond. The thought that crossed my mind was how wonderful it was to see them in a community where they did not have to deal with heavy traffic, random crime, or sidewalk opportunists.

I am not a stranger to the problems of the Developmentally Disabled. My nineteen year old brother has Down's Syndrome and my thirteen year old daughter is microcephalic.

In my brother's case, his retardation is moderate and the possibility of community placement for him is very realistic.

My daughter is not so fortunate, having been tested out to be severly to profoundly retarded. Her handicap is such that she needs constant supervision in a controlled enviornment to provide her with the quality of life to which she is entitled.

Southern Wisconsin Center for the Developmentally Disabled happens to be an excellent facility. My daughter is cared for by people who are well trained and she has the instrction of many very qualified professionals. Aside from her activities at the center, my daughter participates in various community sponsored things, for example field trips to restaurants, shopping centers, fairs, etc.

Bill #S. 2053, "Community & Family Living Amendments of 1983" is a piece of legislation that in the opinion of myself and thousands of other parents, is not appropriate for the entire retarded population. I am very much against the bill and ensuing heartache it would bring to so many handicapped individuals and their families.

I feel that I am a fairly objective person. In fact, I am a past County ARC President, but I will do everything in my power to see that this unfair bill, #S. 2053 does not get passed, because I love my daughter very much and I want her to have the best life possible.

Thank you for your consideration.

Sincerely Yours,

Janna DeArmond Waldeck

Janna DeArmond Waldeck

Please, Mr. Roderick
hear my concern.
Thank you.

W

Mauston, Wisconsin
August 28, 1984

Dear Mr. DeArmont;

This letter is in regard to bill number S. 2053. Community & Family Living Amendments of 1983.

The passing of this bill would not be favorable for my son, who is living in Central Wisconsin Colony. I am sure he could not cope living in a group home.

He is 31 yrs. old and been gone from home since 6 yrs. of age. He doesn't talk, he has seizures, feeds himself but eats mostly with his hands, toilet trained, but has accidents, does walk but gets lost and disoriented. He has the mentality of a three year old. Which I don't feel a group home is the place for him.

He had been placed in a nursing home and another center in Wisconsin, about ten years ago and had to be brought back to Central Colony. Being in these places upset him so much, he began having seizures all the time. And was finally returned to where he is being cared for now.

I think having him in an institution is the one and only place he could be in. He gets the Care, supervision, and medical attention he needs. I feel that they are taking away something that is really needed for these patients. There has to be a way they can provide Medicaid funds for these institutions, which are so badly needed. And I am sure that anyone who has a severely retarded or handicapped person would want them in an institution rather than a group home. And if your not one of these parents, just thank God.

Sincerely,
Mrs Dorothy Wallace
107 Sara Lane Apt. 23
Mauston, Wisconsin
53948

W

arc

WASHTENAW ASSOCIATION FOR RETARDED CITIZENS

290 SOUTH WAGNER ROAD, ANN ARBOR, MICHIGAN 48103
662-1256

Dohn Hoyle, Executive Director

Sarah C Jaworowski, President

August 28, 1984

Mr. Roderick DeArment
Chief Counsel
Senate Committee on Finance
Washington, D.C. 20510

Dear Mr. DeArment:

Please accept this letter of support for S.2053 in reference to the public hearing of August 13th. While we were unable to attend the hearing in Minneapolis, and are also disappointed that no hearings are scheduled in Michigan, we did wish to go on record.

In Michigan, and in this community, we have watched the phasing out of our large institutions. We have of course, seen the conmeasurate return of their former inhabitiants to the community. The results have been wonderous, surpassing even the fondest dreams of those of us who advocated same. There can be no doubt the Developmentally Disabled are far better and for more humanely served in the community. Conclusively, they grow and develop in the versus congregate settings.

We have startling, striking examples: a gentleman in an institution for 27 adult years, now makes more money than I pay my staff, owns his own home and is a contributor paying income and property taxes, not a consumer of Medicaid services. Others have stopped guarding their food with both arms and eat at a normal pace. Some now only tie their own shoes or partially dress themselves. All have incressed in some measure, their self-care or self-answering. All lead vastly enriched and usually much safer lives.

Please consider this letter testimony as to the need for restructuring of Title XIX to accomplish further, the serving of persons with developmental Disabilities in their communities. Provide the ability to phase out large congregate settings in favor of smaller more normal nurturing opportunities. Help prevent further institutionalizations, by enabling families and others to be supported and to serve people in their families and in their communities

I remain available to support this position, and am,

Sincerely,

Dohn Hoyle
Executive Director

LMB/rec

A United Way Member Agency

TO: Mr. Roderick DeArment
Chief Counsil & Staff Director
Washington, DC 20510

FROM: Leonard & Betty West
23309 62nd. St. Salem, Wi. 53168

8-10-84

SUBJECT: Chafee Bill S-2053 "Community & Family Ammendments Act".

Dear Mr. DeArment:

We are against the proposal of the NARC-US to close the State Institutions. We were never consulted, did not vote on the issue, therefore the delegates vote does not represent us.

We are strongly opposed to closing S. W. Center!' We are strongly opposed to The Chafee Bill S-2053.

Our Son Thomas J. West 5285 SWC was admitted to the Center Jan. 5, 1968. He has no speech except crys and screams. He was a very disturbed boy. (Can become very disturbed to this day in the wrong enviornment). Ordinary daily happenings would cause him to scream piercingly, lashing out with vicious aggressive behavior, biting, kicking, scratching at the nearest victim. Breaking windows with his bare hands--dangerous to himself and others. The numerous doctors we took him to said, Emotionally disturbed, Autistic, Severely retarded. We only knew the obvious--he could not cope with so called "normal living conditions".

Tom is now 28 years old. SWCenter has been his home for 16 years. With the proper medication and firm, kind discipline, we have seen him calm down. Tommy is a loner, he does not warm up to people. Even with proper medication , at times he still has severe aggressive behavior, (Will bite his peers when provoked , or for no apparent reason. At the Center the Aides know how to handle it promptly and efficiently. He thrives on the structured routine, it gives him security.

In a community group home we feel Tom, and a large majority of residents would not receive the excellent 24 hour care, plus hospital and dental services available at the Center. The point is he, and others like him do not have normal behavior, so why force them in a so called "normal community group home".

We are strongly opposed to closing the institutions that are totally equipped to care for the mentally disabled. It would be a backward step. We are certain it would backfire, causing untold suffering and confusion, and useless spending.

Sincerely:

Betty M. West
Leonard J West

w

August 24, 1984

Dear Mr. Hedrick Bellmon/

I'm writing to let you know why my husband and I strongly opposed the S.2053 Bill "Community and Family Amendments of 1933".

If this bill passes and it means closing all state institututions we will be greatly affected.

We have our retarded son Billy in Southern Center and although at first hesitated to put him there we have never regretted it and can't give them enough credit for all they have done and are still doing for him.

He weighed 178 pounds at 10 years old when he went there. We tried to curb his appetite but he'd manage to even hide food without our knowing. We even tied ropes around the refrigerator, so he couldn't get in! He had other bad habits like cutting his hair tearing paper into strips etc. but the worst ones he liked motors and was facinated with fire, matches, cigarette lighters, stove jets etc. When he was 5 years old he set himself on fire and nearly lost his life. He did lose all his toes and part of his left heel. After he recovered he learned to walk again even tho he was handicapped. When I'd get the heel almost healed he'd scratch it open every so often, but I managed to keep it under control. For the next 5 years we still had problems, but although we were advised even before his accident to put him in an institution, we refused thinking we were doing the right thing- that love was the most important and who could give him that more than his own family! Now we regret we didn't take action. Things might have been different and we blamed ourselves for what happened but no matter how close we watched him he had a determination and managed to get into problems. We then decided something had to be done so through a Social Worker we got him into Southern Colony as it was then called.

After 1 month under their excellent training we could see changes in him. He no longer tore paper into strips which was something we couldn't do. They are special people and are gifted teachers. God bless them! Billy has come a long ways, but he still has a behavior problem at times. Several times they have tried to place him closer to hime, but they couldn't fill his needs. He needs strict supervision. They did try putting him in the Beloit Convalescent Center, but after 3 or 4 weeks he was returned to Southern Center. We were grateful they did, because he wasn't happy in Beloit and wasn't getting the care he needed and got into problems with other patients by taking their cookies, candy etc. also the sugar cubes on the dining room tables. After he was back it effected him emotionally.

We feel if he is moved into a different lifestyle now after he is so well adjusted it could harm him as he is very emotional and gets upset easily.

He's in a wheel chair most of the time, because of his leg and ulcerated heel which flares up every so often and he needs daily care. He's under a doctor's care both physically and emotionally because he has this behavior problems especially if he's teased. He's also on a diet and is slowly losing weight. They now have him down to 145 pounds, but he needs to lose more.

Billy is a very lovable child, but he likes a lot of attention and interferes in others conversations. They have him on a very good program and are teaching him as much as he's capable of and we feel he couldn't be in a better place. He's happy there and its his home away from home.

He's been in the Special Olympics and is very proud of his medals and ribbons and he feels like a MAN!

We bring him home every holiday and his birthday but after 3 or 4 days he needs to go back. He starts slipping back and thinks he can get away with things.

We love our son very much and want the best for him which we feel he now receives.

We are now senior citizens and I am under a doctors care. We never worried as long as he was there, but this news has given us great concern.

Thank-you for your kind cooperation and may God guide you in your decision.

Sincerely,

Mr & Mrs Ernest Sidner

P.S. Southern Center is a training school and a home with love. We highly recommend it to stay open! We don't consider it as an institution and hope it can give other parents with similar problems the help, peace and comfort we have received.

P.S.

I know I sent you a similar handwritten letter but was able to get one typed. I thought it would be easier reading. Hope this reaches you in time.

Thank you again for your prompt attention to it.

Hoping you will consider my written testimony in the hearing in [illegible] which was held in Mission [illegible] 13th by [illegible]

W

August 29, 1984

Dear Mr. De Arment:

Please consider this letter as Written Testimony for the hearing on S. 2053 held in Minneapolis on August 13, 1984 by Senator Durenberger.

My husband and I are totaly against bill S. 2053, "Community & Family Living Amendments of 1983."

Our 26 year old daughter is severly retarded and needs twenty four hour care. We do not feel our county or city would sufficiently fund group homes There are too many needs for local and county taxes to go and this type of care would be a last consideration

We find Wisconsin institutions very acceptable.

Please reconsider and do not pass this bill.

Sincerely,

Mr. & Mrs. Duane Willadsen

W

818 Terry Place
Madison, WI 53711
August 24, 1984

Mr. Roderick De Arment
Chief Counsel & Staff Director
Committee on Finance
U.S. Senate - Room SD 219
Washington, D.C. 20510

Dear Mr. De Arment:

Re: S. 2053

Please consider this letter as written testimony for the August 13, 1984 hearing on S. 2053 held in Minneapolis by Senator Durenberger.

We support concern for the expansion of <u>good</u> community-based services to the Developmentally Disabled. And we plead that appropriate resources be continued for existing institutions that deliver excellent quality services. We consider Wisconsin institutions outstanding.

Our son, Allen, born December 26, 1944 has resided at Southern Wisconsin Center for the Developmentally Disabled since August 10, 1951. "Diagnosis: AAMD: Severe mental retardation associated with trauma or physical agent. Mechanical birth injury. BK amputation on left with prosthesis."

During Allen's seventh year in his family home we sought placement facilities in our community and the contiguous counties. Private sector and nationally renown religious domiciles would not accept Allen - "patient care/staffing ratio too great." Ultimately we realized that Wisconsin institutions were a very acceptable and proven alternative to the community placement that we could not accomplish in 1951. Allen receives excellent medical care and enjoys compassionate rapport with a dedicated staff of skilled professionals that motivate him to reach for an enriched life.

We commend to you the Southern Wisconsin Center for the Developmentally Disabled as a model of excellence as you proceed in your important work.

Sincerely,

Allen E. Wilson Christine Wilson

Allen E. & Christine Wilson
Parents/Guardians of Allen Wilson, Jr.

W

JOHN WILSON
2330 CENTER AVE
MADISON, WI 53704
(608) 244-8862

Written Testimony for the Hearing on S 2053,
"Community and Family Living Amendments of 1983",
which was held in Minneapolis on August 13, 1984
by Senator Durenberger

My brother, Allen, is 39 years old but severely retarded with the I.Q. of a 3½ year old. His leg has been amputated above the knee and, needless to say he needs intensive care. The Southern Wisconsin Center for the Developmentally Disabled has very satisfactorily provided this intensive care and love for over 30 years. I am concerned that the provisions of S. 2053, though probably a fine concept for more independent retarded individuals, would deprive my brother of the specialized skills required for his care. Group Homes having fewer and varied types of patients would not be able to provide specialized care for the severely retarded — or at least their ability to do so should be tested on a small scale before all the severely retarded such as my brother are deprived of specialized care.

Currently, my brother has ready access to specialists in schooling, nurses, doctors and specialists who have invented a suitable prosthesis for his amputated leg.

Decentralizing care will be at the cost of providing specialized care. Therefore, bill S. 2053 should be written to discriminate carefully between the more independent and the more severely retarded. Otherwise I strong oppose the bill.

Sincerely,

John M. Wilson

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Aug 20th
[redacted] 1984

RE: Bill S-2053
Community and Family Living Amendments Act

Dear Sir:

Our entire family is strongly opposed to the passage of this bill.

My brother, whom I am legal guardian of, has been institutionalized for thirty years. He along with many others at Southern Colony in Union Grove, Wisconsin, have received excellent and professional care. He developed retardation from a brain abscess when just an infant. He is an epileptic, severly crippled, speaks very little, and is incontinent of all body functions. Along with these problems are many, many other health problems, far too many to list.

He was placed in a regular nursing home for several months, and was considered to be transferred to a group home on several occasions. None of these alternatives worked for a person with his type of numerous afflictions. My brother is fifty-four years old, and requires around the clock nursing care.

I am sixty-eight years old, I could not possibly attend his care at home. My brother is a full-time job for a trained nursing staff.

I love and want the best care possible for my brother regardless of his condition. I feel any alternate care for him would be detrimental to what is left of his health. I implore you to please search your heart before passing this bill.

Sincerly,

Anna + Ben Wimmer Sr

Anna and Ben Wimmer
5249 Gideon
Zion, Illinois 60099

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August 16, 1984
1021 Bluebird Lane
Union Grove, Wi.
53182

Mr. Roderick De Arment
Washington, D.C. 20510

Dear Mr. De Arment,

We are strongly opposed to Bill S-2053, "Community and Family Living Amendments of 1983."

My son has organic brain disease. From the time he was first diagnosed, we were advised he needed constant supervision. We kept him at home for the first 17 years of his life. He would just walk away from home. He is taking very much medication for seizures. He cannot possibly be on his own.

Southern Wisconsin Center at Union Grove, Wi. is the best place for our son. Thank you.

Mr. and Mrs. Norbert Windsor

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6800 N. 76TH STREET P.O. BOX 23221 · MILWAUKEE, WISCONSIN · 53223 TELEPHONE: (414) 353-5000

WISCONSIN
LUTHERAN
child & family
SERVICES
"Carry each other's burdens"

Pastor E. F. Lehninger, Executive Director

August 14, 1984

Mr. R. DeArment, Chief Counsel & Staff Director
Committee on Finance, United States Senate
Room SD 219
Washington, D.C. 20510

Dear Mr. DeArment:

I would like to have the following entered as written testimony for the hearing on S.2053. I believe that the passage of S.2053 "Community & Family Living Amendments of 1983" will have damaging effects on many profoundly retarded people. As I understand it, the goal of the bill is to withdraw Medicaid funds from state institutions for the retarded and redirect the funds to community board facilities.

As the parent of a profoundly retarded and physically handicapped child who has lived at the Central Wisconsin Center for the Developmentally Disabled in Madison, Wisconsin, for the past four years, I am very much opposed to this measure. While I wholeheartedly support the use of the local community boards for providing programs for the retarded, there are however some retarded people who because of the multiplicity and complexity of their handicap do require institutionalization. Not every retarded person can benefit from being mainstreamed back into their local community.

The concept of the "least restrictive environment" that resulted from Public Law 94-142 often is used to imply that institutionalization of a handicapped person is bad. I believe there are times when placing a severely handicapped person back into the local community which may not have the necessary support facilities is in reality placing that person in a very restrictive environment. On the other hand, if that severely handicapped person is in an appropriate institution which has developed a delivery of service plan for that individual, he is then in the "least restrictive environment".

While I agree that the vast majority of retarded people do not need any institutionalization, there is, however, a group of severely handicapped people who definitely do depend on the institution for their survival.

Thank you,

John Juern

John Juern, Ph.D.
Psychologist

JJ:ls

SOCIAL SERVICES • SKILLED NURSING CARE • HOME FOR THE AGING
MEMBER CHILD WELFARE LEAGUE OF AMERICA / MEMBER AMERICAN ASSOCIATION OF HOMES FOR THE AGING

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115 Elk Acre Dr.
Estill Springs, Tn.
August, 11, 1984

Mr. Roderick DeArment
Chief Counsel &Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, D.C. 20510

Dear Sir:

This letter is being written in objectio of bill S. 2053,

"Community and Family living arrangements Amendments of 1983".

This bill,if passed, would remove our 36 year old son from Southern Wisconsin Center at Union Grove(and many others like him). He has uncontrolable epilepsey, is retarded, from birth, and has other health problems. He is receiving the best possile treatment from trained personnel of all kinds. We are in our mid-seventies and could not handle him.

A Group Home would be out of the question. Such handicapped and helpless persons needthe staff and facilities these institutions can and do supply. Many public servants have seen to the upgrading of handicapped homes and the results, in our opinion, have been noticable.

Furthermore, has the cost of the multitude of these "Group Homes" been figured? There is rent, utilities, food and preparation, nurses maintenance, overseers, District supervision, etc.just as a start. Whereas in an institution all facilities and trained personnel besides hospitals and staff are right there. Schooling is provided in all phases of rehabilitation.

Another problem is the placing of such "homes" for retarded in residential areas. The objection, even lawsuits have barred them. They end up in most unfavorable locations.

Please don't destroy the years of work by former compassionate Congressmen and women who have done so much to up-grade these needed institutions.

Sincerely,
Josephine Wolf
Myron J Wolf

1536 Scenic Loop
Fairbanks, Alaska 99701

August 14, 1984

Mr. Roderick DeArment
Chief Counsel & Staff Director
Committee on Finance
United States Senate
Room SD 219
Washington, DC 20510

Re: S. 2053

Dear Mr. DeArment:

I am writing to voice my heartfelt opposition to S. 2053, the "Community & Family Living Amendments of 1983." There are retarded individuals in state institutions who would suffer if they were removed from the kind of care they can only get in an institutional setting. My son, Jimmy, is one of them.

Jimmy is 27 but is mentally only 3 years old. He is deaf, autistic, self-abusive, cannot talk and occasionally has seizures. He cannot or will not relate to other patients and becomes aggressive when frustrated.

The one-to-one attention he has received at Southern Center in Union Grove, Wisconsin has helped him become less dependent in some ways. He is able to dress and feed himself but still requires assistance brushing his teeth, using toilet and other hygiene activities.

There is no realistic expectation that Jimmy will ever significantly improve. At present he is as comfortable and as happy in his own way as he can be. This would be shattered if he was to be moved to a family living environment. There would be no provision for the kind of individual care he needs to simply keep himself clean, let alone satisfy other house living requirements. And the trauma and frustration he would feel in such a setting would result in intensifying his aggressive and self-abusive behavior. I cannot believe that such a situation would not result in degrading Jimmy's life and the well-being of those around him.

There may be many institutionalized individuals for whom the family living environment might provide enormous benefits. Jimmy is not one of them. His stage of development is too basic and his handicaps too severe to benefit from a family situation.

Jimmy has received excellent care at Southern Center. For Jimmy, and I imagine many others like him, institutionalized care is the only alternative.

Very sincerely,

Norma Wynen

Norma Wynen
(Mother of Jim Brandes)

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1518 N. 60th St.
Milwaukee, Wis. 53208
August 22, 1984

Dear Mr. DeArment,

I am in complete support of Bill S2053 and urge its' immediate passage. I feel retarded citizens have the right to live in their home communities, if they so choose. At this time, lack of funds for community services deny many this right.

Please, include my letter as testimony at the regional hearing to be held in Minneapolis August 24th.

Respectfully,
Marianne Wolff

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August 6, 1984

Roderick A. DeArment, Chief Counsel
Committee on Finance
Washington, D.C. 20510

Dear Mr. DeArment:

I would like to testify on August 13 in support of the "Community and Family Amendments." Following is my testimony.

"My name is Ted Zimpel. I lived at Faribault State Hospital for 32 years and 7 months. I went there on May 2, 1939 when I was nine years old. I went there because the school board and teachers in Isanti County said I was too slow. They had a meeting and then the county sherrif drove me to Faribault.

When I was at Faribault State Hospital, I worked many jobs in the kitchen, cooking, milking cows, cleaning up other residents. I earned 50¢-$1.00 a month. I worked in the dairy for four years milking cows at $1/month.

For punishment - when I did not want to work - we were beaten by long brushes. Or made to clean up other residents who were lying on the floor and had wet on the floor. Or made to scrub the floors 2-3 times a day and given cold showers. One time I ran away because I was sick of the abuse and was put into lock-up.

In 1972, I was discharged and moved out. I now live in a board and lodging home and work at an insurance company in Eden Prairie baking, vegetable preparation and dishwashing. My life has been good since I've been out. It's been good because, although I've had some financial problems, I'm responsible, know I can live on my own and fulfill my responsibilities.

I support this bill. I believe there are a lot of people still in the state institution who should be out. I think even the most handicapped person can be out in group homes and be rehabilitated.

I believe institutions should be closed - not in ten years, but right away. "

Sincerely, Mr Paul Teddy Zimpel

Ted Zimpel
2430 Pillsbury Avenue South
Minneapolis, MN 55404
(leave message at 721-1696)

cc: Senator Dave Durenberger
1020 Plymouth Building
12 South 6th Street
Minneapolis, MN 55402

353 Russell Senate Office
Washington, D.C. 20510