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Testimony

of

MELVIN D. HECKT
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before the

SUBCOMMITTEE ON HEALTH

of the

UNITED STATES SENATE
COMMITTEE ON FINANCE

on

Community and Family Living Amendment of 1983
S.2053

February 27, 1984

WASHINGTON, D.C.

Summary of Points

I Federal Medicaid should not be withdrawn from all state and community institutions.

a. Almost all would close or return to the warehousing of the past.

b. Parents and/or retarded people would lose the freedom to choose--the institution or the small community home as the most appropriate and least restrictive.

c. If would dump many out of institutions against their wills, and their parents wills, and into inappropriate community residences and services.

d. It would deny residential and other services to those who have no alternative.

e. It would damage the already low self-esteem of those who are admitted and then demitted from the small homes.

f. The mass transfer of all is draconian and mindboggling - the human suffering of residents, parents and employees - the economic loss and waste.

II. S-2053's arbitrary small limitations for all future residences should be rejected.

III. Federal Medicaid should be extended to community services in S-2053.

a. It is good for many, but not for all.

b. Increased appropriations now should save tax dollars in the future by prevention or delay and diversion from the more expensive community and state institutions.

IV. **Recommendations**

a. S.2053 should be withdrawn or killed NOW.

b. The Federal Government should not force or plan closure of all or most institutions now. The state of knowledge is too soft.

c. States must decide, or play a major role in, any such closure decision.

d. More experience with and study of the federal "Community Care Waiver" law is necessary.

I am Melvin D. Heckt, a Minneapolis lawyer, and father of Janice, age 32, a severely mentally retarded young lady whose home is the Faribault State Hospital.

I speak on behalf of my daughter, and for many parents, relatives and guardians of citizens who are mentally retarded and who live in state or community institutions.

May I express our deepest appreciation to you, Senator Durenberger, and to each member of this subcommittee, and to Congress for the Medicaid law and appropriations which have enabled my state to make substantial improvement in the quality of care for the 2,211 residents in our ~~eight~~ seven (7) state institutions, and for the 5,000 residents of our 300+ (311) community ICFMR facilities, of which 2,300 residents live in 41 community institutions. Our success today would not have been possible without federal and state Medicaid funding.

For 30 years, I have joined with other members of the Association for Retarded Citizens in fighting the long battle for the development, expansion and improvement of community and

institutional services for all citizens who are mentally retarded. As a consequence of that involvement, study and experience, I strongly support extending federal Medicaid funding to those additional community services provided in S.2053, and just as resolutely oppose both the withdrawal of substantially all of that Medicaid funding from all state and community institutions, and the arbitrary size limitations for new community residential facilities contained in the bill.

S.2053 represents the worst of all worlds for many mentally retarded citizens who reside appropriately in state and community institutions if Medicaid funding is withdrawn, and the best of all worlds for many infants, children and adults who appropriately could continue to live with their parents, or in foster homes, group homes or semi-independent living facilities only if Medicaid funding is provided.

S.2053 THE WORST OF ALL WORLDS

However well-intended, S.2053, the "Community and Family Living Amendments of 1983", requires of its supporters an irresponsible leap into dangerously uncertain waters. The architects of this questionably designed and imprudently proposed legislation have advanced a blueprint which creates many more problems than it seeks to correct.

Based on my independent examination of widely dispersed research studies, conversations with hundreds of parents and

numerous experts, and my own personal experience, I am convinced that if S.2053 is adopted, most, if not all, of the following results would develop from the incautious leap previously mentioned:

1. All state institutions would be closed in 10 years or less, or, if some states decided to fund the entire cost of those institutions, the quality of service would return dangerously close to the warehousing and substandard care which prevailed in them so disgracefully 15 years ago or such states might maintain existing standards, pay the entire cost of said institutions, and reduce the funding of existing necessary community services by the amount of the loss of the federal Medicaid funds.

2. Almost all community institutions (defined as those having more than 15 beds) would be forced to close their doors to mentally retarded citizens in 10 or 15 years because those community institutions in many states derive 45 to 80 per centum of their operating costs from federal Medicaid funding.

3. S.2053 would deny to mentally retarded persons, and to their parents, relatives and/or guardians, the right to choose the state or community institution as the most appropriate and least restrictive among the current options.

4. S.2053, in a baronial disregard of parental wishes or opinion concerning the best interest of their retarded sons and daughters, would force many mentally retarded people - against their wills, and against the wills of their parents, relatives and/or guardians - to leave appropriate community and state institutions, and would dump them, almost indifferently, into inappropriate community residential facilities. Ironically, that ill-chosen curtailment of residential and programatic options would, at the same time, deny appropriate small group home community services for those who now live in community or institution settings, but who want and are able to live in smaller community facilities, yet could not secure admission to them because beds and programming would be taken by those from the institutions who would be transferred to them inappropriately and unwillingly.

5. The bill's untested and excessively risky "solution" would force the removal nation-wide of almost 180,000 retarded persons from existing state and community facilities which have more than 15 beds. The turnover problem inherent in such a mass transfer of mentally retarded persons is as mindboggling as its ramifications are endless. It is draconian. It is difficult to predict the economic cost and human suffering of such a move.

6. This proposed legislation would deny residential and programatic services to those who have no alternative but a state or community institution. This is true especially for those profoundly and severely and multiply handicapped retarded who live in sparsely populated areas of America, and who require 24-hour nursing, and other professional care. It also eliminates a vital resource for those who have been demitted from the foster or small group home, or whose foster or group homes have gone out of business, or lost their licenses, or who have tried the small foster or group homes and found living in them unbearable. It is safe to say that sometimes 6 normal adults or 6 retarded adults cannot live under the same roof. Parenthetically, it is important to note that in the past several years, most admissions to Minnesota's state institutions have been those discharged from group homes or other community facilities.

7. The closure of all state and community institutions will result (notwithstanding the best intentions of the bureaucracy) in many residents now therein being unloaded, nil admirari, into inappropriate community residences and ineffective programs. What is even more horrifying to consider is the possibility that those unloaded will be provided with no program or residential service whatsoever.

In the past, the efforts of some states to reduce institution populations have resulted in horrible dumping. Indiana dumped 4,000 institutionalized residents into nursing homes without adequate programs. Illinois unloaded thousands into huge, rundown, downtown Chicago hotels located in high crime areas. Missouri's plan was nearly a shambles, and even in Minnesota, which to date has an excellent record of reducing its mentally retarded state institutionalized population, there has been some dumping of young adults into nursing homes for the elderly, and others into larger, more restrictive community environments than existed in their former state institution home. Others have been injured by medically prescribed drug overdoses in the community, and have had to return to the institution.

I am not convinced that the monitoring, licensing and individual program plans will eliminate dumping if the federal and state dollars stop flowing.

8. However unintentional, and perhaps totally overlooked, consider the psychological damage facing those residents who, for the sake of expediency, are transferred to group homes, and then are kicked out. If they know their self esteem is low, what explanation can be given to those so afflicted that will abrogate the further decline of self worth brought on by

another, and then another, and then another dismissal? Not all of the elderly retarded residents in institutions are Bill Sackters; nor will all have the good fortune to find such good and supportive friends as Bill. Some have lived in the institution for 50 or more years, and do not wish to leave. How can we totally disregard their feelings, and their rights? Some retarded people of all ages exhibit great difficulty adjusting to change. Others can adjust. But still others cannot make changes without disastrous results.

9. S.2053 leaps recklessly to a number of incorrect conclusions and unsupportable assumptions. Among these is the notion that adequate monitoring of small group homes will be guaranteed. Under other less crucial circumstances, if that idea were not so pretentious, it might be described as quaint. For example, if Minnesota were to require 6-to-a-household limitations for those currently residing in our state's ICFMRs, and in our state institutions, it would need 1,182 community residential facilities as opposed to the present 300+ ICFMRs and eight (8) state institutions now in service. The cost of monitoring those additional facilities necessitated by S.2053 would be gigantic; the dumping and demissions would be catastrophic; and, administratively, an ongoing nightmare would be created. Quis custodiet ipsos custodes?

10. Among other less less-than-infallible conclusions drawn by the promoters of S.2053 is the claim that costs are less expensive and living conditions are better for all mentally retarded citizens if they reside in small foster or group homes in the community rather than in state or community institutions. Nothing resembling acceptable evidence is offered in support of that claim. Conversely, from across the nation, and within many disciplines, respected voices are heard cautioning against premature acceptance of the studies projecting large cost-savings or superior living conditions for all mentally retarded people if only they move lock-step into the small foster or group homes in the community. The more realistic expectation is that the proponents claim is correct for some and incorrect for others. Exaggerated projections of cost-savings can only come back to haunt many retarded citizens in time.

11. The same thesis further declares that if all state and community institutions were to be closed within 10 to 15 years, automatically small foster or group homes would be located, developed, funded and staffed with experienced and caring employees for those mentally retarded persons who have been discharged from them, and also for those living at home but in desperate need of such community services. Again, that helter

skelter plunge into unchartered waters. One almost would conclude that the proponents have overlooked a number of salient problems. For example, high interest rates, high building costs, housing shortages, low per diem rates for profit and non-profit providers, unwillingness of some states to appropriate more tax dollars, the logistical problems of closure and locating new facilities; all have a significant bearing upon achieving the proponent's objective.

Likewise, how can state or community institutions continue to reduce their populations, and revenues, and still meet the high standards established by S.2053 and not be sued under Sec. 5 (a)(i) et seq? Does anyone actually believe that such a massive nationwide shift of people can be well-coordinated among all of the cooperating county, state and federal agencies?

Now, for the purpose of clarity and openness, and wishing to state my unease with S.2053 as specifically as possible, may I ask the subcommittee to consider the following questions and criticisms:

1. Page 2 - Lines 21-31 (b) (2) (3).

   Unless changed, this section would deny medical assistance to persons who have resided in an institution for a period of two years, and who have no other alternative for residential placement. Likewise, I think it is both

ridiculous and cruel to designate such a short time duration for care, treatment, and habilitation of some persons who are mentally retarded.

2. Page 3 - (c) (1) (D) Specialized Vocational Services

Is it not conceivable that the inclusion of vocational and employment services in medical assistance funding might drain off dollars for existing services to such an extent that now in-place community services will receive less funding than at present?

If that be the case, then I believe that some of these services should be excluded from medical assistance funding.

3. Page 6 - Lines 7-18 (2) (B) (i) and (ii).

Exceptions and alternatives must be provided to any bed size limitation for a facility. This does not distinguish between the need for providing residential services for children apart from those established for adults and severely retarded, and it fails to consider the special needs of the profoundly multiply handicapped, high intensive medial and 24-hour nursing care person as contrasted with the mildly or moderately retarded person without such handicaps.

(C) Line 25 (iii)

The suggestion that in order to receive medical assistance, all profoundly retarded, multiply

handicapped people shall be located in residential neighborhoods, wherein they would be encouraged and enabled to participate in the prevailing living, working and service patterns of such neighborhoods, either amounts to a classic case of sheer folly or represents another definition of the word PROFOUNDLY.

4. Pages 6 and 7 - (h) (2) (D) (i)

In the section defining the inter-disciplinary team, S.2053 states that professionals and retarded people shall be part of the team, and "when appropriate, the parents, guardians, next of kin, or next friend of such individual" may be involved.

Does it not seem more-than-somewhat illogical to insist that a profoundly retarded person who can't understand or communicate or make certain decisions be given a place on the inter-disciplinary team while, at the same time, denying membership to a parent because someone, presumably a professional, has determined that the participation of a parent, relative or guardian is irrelevant "to the habilitation or rehabilitation of such individual."

Parents of profoundly and severely retarded sons and daughters have been making many decisions for the lifetimes of those persons who do not have the ability to do so. How

can anyone summarily pre-empt from them that natural right? Or deny to them that loving involvement? Before a parent is precluded from inter-disciplinary team participation, should not the Court so order that exclusion?

5. Page 8 - Line 2 (B)

Though the plan calls for continuity of medical assistance for severely disabled individuals who reside in a facility or institution that ceases to function, it provides no assurance whatever for the continuation of residential services.

(F) Refers to a periodic independent monitoring or review of the quality of medical assistance provided, but fails to specify the time intervals involved. Could they be ten years apart?

6. Page 9 - Line 6 (H)

Deals with maximum efforts made to provide employment of former institution employees affected by the transfer of severely disabled individuals to community facilities, but nowhere in S.2053 appears anything resembling assurance or guarantee that those efforts will produce positive results. Other questions regarding employee loss are ignored or overlooked. Herewith, a sampling:

(a) If S.2053 passes, will not the best professionals, and lay staff, depart the facility as quickly as possible? Who would remain facing sure dismissal in 10-years, or less? May that not have an adverse affect upon many residents?

(b) What of the former mentally retarded residents who are now gainfully employed at institutions? About 50 such workers are presently employed in Minnesota? Is it reasonable to think that they will be able to find employment elsewhere?

(c) Many institutions have excellent ongoing in-service training programs for those who work with the mentally retarded and other handicapped persons. How can we retain the experience, know-how and priceless empathy and enthusiasm of those employees if we threaten their jobs?

7. Page 11

Temporary Increase in Federal Payment - Section 3 (7)

The 5 per centum incentive to place severely disabled persons in the community promises dumping just as surely as the counties' financial incentive to place them in institutions guaranteed it. Both were/are wrong. Appropriate placement must be the prevailing criteria. Incentives of a fiscal nature can only insure dumping.

Forced to confront the possibility that S.2053 might be enacted, I find myself caught in a crossfire of frustration, astonishment, uncertainty and parental concern - a combination of eviscerating emotions not unlike the helplessness felt by a black person who was denied the right to vote, forced to sit in the rear of a bus and refused the freedom to eat in a public restaurant.

My daughter, and thousands of mentally retarded persons like her, by this legislation will be told that they have been denied the right, and the choice, to live either in a state institution or a community-based facility if any of these abodes exceed the new, mandatory resident limits established by S.2053. Instead, imperiously, they will be forced to live in a house sheltering from 1 to 15 residents, in a community not of their choosing, a facility chosen for them by some professional or governmental expert(s) who may or may not be governed by what is most appropriate, but rather by how little it costs.

Senator Durenberger, members of the subcommittee, at this point I should like to share with you some of the feelings, opinions, and sentiments contained in letters I have received from other parents and guardians concerning the enactment of S.2053.

"...As with all human beings, there is no 'Oneness' to the retarded population, but a complicated array malfunction within an already complicated structure of human existence. What must be established is a system of care that is capable of matching the myriad of needs present in the regarded population."

DEAN F. THOMAS,
Minneapolis, Minnesota

"...Unless all the resources available at an institution are made available in the community, this proposed legislation is not feasible. Even today, in small outstate communities many of these resources are not available for those already released from State Hospitals. I strongly oppose S.2053 and implore that you and your committee consider this piece of legislation for what it is, a totally inappropriate bill that does NOT protect the best interest of any retarded person."

BERNICE UPIN,
Faribault, Minnesota

"...To rule, as in S.2053, that all mentally retarded Americans must exist in small groups of fifteen beds or less is cruel, thoughtless, and brutal. We need community and state institutions for that portion of the mentally retarded population who need significant, supportive services that a group home could not provide."

FLORENCE M. FISKUM,
Minneapolis, Minnesota

"...The 'retarded' are not ONE group with one problem and therefore one solution. Like all the rest of society, each retarded person is an individual, and what is a good living situation for one may or may not work for another. Please consider all of the possible implications of this amendment. Do not be unduly influenced by its introduction by the Governmental Affairs Committee of ARC-US. So called 'experts' have been wrong many times in the past."

MARIAN D. HELLING
Richfield, Minnesota

"...Horrified at our first encounter with a state institution some eighteen (18) years ago and watching the slow but progressive movement to the present makes us want to sing praises to all the people involved in the program. They have done a tremendous job. Please do not allow it to slide backward. In our opinion there is no best way for all. Some people fit well in residential facilities. Our profoundly retarded son would not fit this mold. He needs close supervsion and he needs training. He is receiving that now and we think he is deserving of it. Our feelings are strong that it would be near impossible for him to receive the same in a small unit somewhere else with small staffing, different caring and attitudes."

MR. & MRS. RICHARD SCHULTZ
Bloomington, Minnesota

"...The end result would be to force large numbers of retarded citizens from their present satisfactory placement in community and state institutions and dump them into inappropriate residential facilities that might or might not be available; all this without the retarded citizens, their parents' relatives' or guardians' input on planning or decision making."

GORDON S. LUNDBERG
Richfield, Minnesota

"...Not to mention the exodus that would occur, from them being transferred from home to home, until one at the bottom of the scale would accept them; to a place, no doubt, where their only interest is making a buck, and the care is non-existent. As an example, I have a twin brother that is retarded who has happily spent most of his 62 years of life in the campus like surroundings of the Faribault State Hospital, where he has always had good care by the staff, who genuinely care about him; who is also wheelchair ridden, and needs a big facility like Faribault with its spacious grounds to roam around in."

LESTER D. LEONARDSON
St. Paul, Minnesota

"...At some point in our lives we are all affected by a mentally retarded person, whether it be our child, a brother or sister, a niece or nephew, or relative of one whom we are associated with. It is a sad commentary that still we are fighting for the rights of the mentally retarded. I urge you to oppose S.2053. I have seen both sides of the coin, having a mentally retarded brother and being a teacher of the mentally retarded.
I would like to request...that you "unofficially" spend a day with profoundly and severely retarded persons, and justify the passage of S.2053..."

BETSY PRATT LONG
Tulsa, Oklahoma

"...One of the premises behind S.2053 is that mentally retarded citizens can and should enjoy the right to move in larger society at will. Many are capable of this, they can go to a job or a movie alone, and there are currently homes (maybe more are needed) that can meet their needs. However, there are many retarded citizens who are not capable of these kinds of activities, who cannot care for themselves or venture into larger society, and to whom living with a large group of peers is of greater concern. To force these individuals to live in a small home with only a few others with whom they can interact is inhumane...."

DANIEL M. FISKUM
St. Paul, Minnesota

BEST OF ALL WORLDS

S.2053 does have some very outstanding provisions which should be approved by Congress. Medicaid should be extended to cover some of these costs:

1. Parents, who otherwise would have to institutionalize their infant or child, should be given medical assistance to enable them to choose to keep their child at home whenever possible. This option may be best for the child and the

parent. In most cases, the cost would be much less than that of the state or community institution or the ICMFR group home. In some instances, the cost may exceed that of the institution, but the child's interest should prevail over the cost argument. Likewise, cost considerations should not force parents to keep the child at home if it is not feasible to do so. Some families can cope while others might be destroyed by having such a child in the home.

2. Foster parents should be an option for children who can't live at home. However, mass usage of foster parents is also fraught with potential for abuse and difficulty in monitoring. For those profoundly and severely retarded who have need of 24-hour nursing care, or who have severe behavioral problems, it may be much more difficult to find such foster parents than some experts admit, and also such foster parents may suffer from the same burn-out as the natural parents. Stability and continuity of care is very important! The use of foster parents for normal children has frequently resulted in some of those children being shunted from foster home to foster home with dire consequences for the child.

3. Small foster homes which need not meet ICFMR standards and regulations are another viable option for some, but certainly not all, mentally retarded citizens.

4. Semi-independent living is another viable option for some mildly and moderately retarded adult citizens. Again, each

individual must be carefully evaluated or disastrous results can and do occur from improper placement. This would not be proper for profoundly retarded adults or for most severely retarded adults.

5. Also, the small ICFMR group home should be a viable option for some of the retarded now living in our state and community institutions. They, and their parents, should have the right to choose and secure admission to such facilities. However, the small group home is not the answer for all children or adults.

In other words, creating more options by extending Medicaid funding gives parents and their sons and daughters a much better opportunity to find the proper residence and program. The prevention, delay or diversion from placement in a more expensive institution or ICFMR facility will save costs for our taxpayers and be better for those who can benefit therefrom. However, too much precaution cannot be taken to prevent cost from being the sole or most compelling criteria in determining what is or is not proper care for the individual person. In Minnesota, I understand that some counties are <u>inappropriately</u> pushing foster home placements for cost reasons only.

Such an extension of Medicaid to those community and family services mentioned above will not eliminate the need for community and state institutions or for ICFMR group homes, but it will hopefully reduce the demand for more of such services and in this way reduce this cost pressure.

There is one other danger I believe should be addressed. Unless Congress and the states increase appropriations in the short run for such family and community services, there is a real danger and probability that present services funded by Medicaid will suffer cut-backs in funding which may substantially curtail the quality of services presently being provided. In the long run, however, such an extension of Medicaid should reduce the amount of or need for increased funding.

THE PROPONENTS POSITION

The proponents of S.2053 obviously believe that all state and community institutions are bad and that all existing community facilities having 15 beds or less are passable, but in the future nothing should be funded by Medicaid if larger than 3 times the average family household size which in my state would be 8.

In trying to convince you that all institutions are bad, they show you publicity of Pennhurst and Willowbrook and I understand Senator Weicker's committee is investigating the 10 worst institutions in the nation, as opposed to any investigation of the best.

They and the media only point out the bad and not the good in our institutions. They should realize that all state and community services, including all residential facilities, vary from quite poor to quite good. Because some are quite poor does

this mean we should destroy all? In our nation there are some bad and excellent nursing homes. Should Congress withdraw all Medicaid funding from all nursing homes because some are bad? Of course not! There are recent developments enabling some who want to live in their homes or in smaller less expensive facilities to receive Medicaid assistance. This makes sense!

The proponents also overlook the vast improvements in physical plants and staffing and individualized programming which have occurred recently in our state and community institutions since the advent of the 1977 ICFMR Law. Many of these improvements have taken place in the past 3 years.

The proponents arrogantly persist in trying to place all mentally retarded people and their parents in the same lock-step, iron pants mold. The proponents know best and the thousands and thousands of parents who have sons and daughters residing in state and community institutions are all wrong. The proponents fail to realize that many of our retarded sons and daughters have much more freedom, much less restriction, much safer surroundings and a more professionally supportive, more loving and happy environment in the larger facility than they would receive in the small group home for 6 or less.

Some of the proponents advance cost saving as the rationale for institution closure, but many now are backing away from that position. In 1963, Minnesota had 6,100 residents in state institutions. This was reduced to 2,300 plus at the end of

1982. To compare the cost of care of the mildly and moderately and even severely retarded who live in community homes with the cost of caring for those profoundly and severely retarded who now remain in the institutions is comparing apples with oranges.

Recommendations

a. S.2053 should be withdrawn or killed now.

b. The Federal Government should not force or plan closure of all or most institutions now. The state of knowledge is too soft.

c. States must decide, or play a major role in, any such closure decision.

d. More experience with and study of the federal "Community Care Waiver" law is necessary. Why? To insure that placement decisions are in fact being made based upon what is most appropriate for each individual and not made upon what is the least costly. Otherwise there will surely be massive dumping or forcing of mentally retarded people out of the State and Community institutions and ICFMR Group Homes into inappropriate small community residences. This would be true whether closure or forced reduction of population were involved.

CONCLUSION

No person who is mentally retarded should be denied the right to live in either a community or in a State or Community institution. Nor should such person be obligated to live in either because there are no other viable options.

The proponants of S-2053 are willing to upset or destroy the entire cart in order to find a few bad apples. The bad apples may be found by this method but the good ones have then already been dumped out.

I appreciate the opportunity to appear before you and to submit this written statement. I am confident this Subcommittee will do what is just and right.

Melvin D. Heckt