

Principal Points of Peter Kinzler, of the Parents Network,
in Opposition to S. 2053 the Community
and Family Living Act Amendments of 1983

1. Parents Network represents 60,000 parents of mentally retarded children who live in institutions in 38 states.

2. We believe, on the basis of first hand experience, that most of today's institutions for the mentally retarded are well run places that provide quality care and training for our children.

3. Community living arrangements for severely and profoundly retarded persons are still in an experimental stage. To date, most community-based residences have dealt with mildly and moderately retarded people, those who can dress and feed themselves and hold jobs in the community. Community experience with severely and profoundly retarded people-- those whose trainability is very limited and who need around-the-clock care-- is very limited and has not been subjected to rigorous analysis. Many expert observers in the field suggest that other factors--such as the grouping of residents and the qualifications of staff-- are more relevant to development.

4. Existing data on the relative costs of institutions and community living arrangements are contradictory and inconclusive. • Most of the studies are fatally flawed, in that they tend to compare the costs of less retarded individuals in the community with those of the more" severely retarded residents of institutions, and they compare a different constellation of services. Where similar residents and services are compared, the costs appear to be about the same. There is no reliable data to support the contention that even one more person can be served for the same dollars, nevertheless that two to three times the present population could be served.

5. Parents have a number of questions about what would happen to our children in the community living arrangements envisioned in S. 2053. How would the many services now provided at institutions--from different types of therapists to medical care-- be provided ? Would bad apples among the staff be weeded out rapidly ? Could Medicaid monitor 100 times the number of living arrangements they now monitor with any reasonable assurance of maintaining quality ? What will happen to the residents who are left behind in institutions when a financial crunch occurs ?

6. Some actions can be taken now to better meet the needs of all severely and profoundly retarded people. One, the states and the federal government can provide more money. Two, the bias in Medicaid in favor of institutional funding should be eliminated, building on the present waiver program. Three, most mildly and moderately residents of institutions-- those most demonstrably capable of benefitting from living in the community-- should be moved there. Finally, we must develop a continuum of services from private homes to group homes to institutions to assure that the individual needs of the retarded-- and not the needs of those with an ideological predisposition--are best served.

Statement of Peter Kinzler

on behalf of
the Parents' Network
and
Parents and Associates of the Northern Virginia Training Center
in opposition to
S. 2053
the Community and Family Living Act Amendments of 1983
before the Health Subcommittee
of the
Senate Finance Committee
February 27, 1984

I am testifying today as the parent of a severely to profoundly retarded son who resides in an institution, on behalf of the parents of that institution and on behalf of the Parents Network, an informal organization of more than 60,000 parents of mentally retarded children who live in institutions. The Network sprung up more or less spontaneously in the Summer of 1983 in reaction to a legislative proposal by the Association for Retarded Citizens to phase out, over a 10 to 15 year period, all Medicaid funding for institutions for the mentally retarded. This concept has been incorporated into S. 2053.

We are generally very satisfied with the care our children are receiving in today's institutions, which more accurately deserve the name "training centers." While we are well aware of the need for more community living arrangements--and fully support additional funds for their creation-- we believe they are needed to supplement, not replace, institutional care. What is needed is a continuum of care so that retarded citizens can receive the most appropriate care to fit their needs. Unfortunately, S. 2053 would fund more community living arrangements by cutting off federal Medicaid funds for institutions. This approach would surely mean the closing of most if not all institutions. There -

fore, as the parents of the children who would be most directly affected by this legislation, we vehemently oppose enactment of S. 2053.

Let me state to you as clearly and succinctly as I can the basis for our opposition.

Most of Today's Institutions for the Mentally Retarded Are Well Run Places that Provide Quality Care and Training for the Residents

Thanks to years of effort by thousands of people— including many members or former members of the Association for Retarded Citizens— today's institutions no longer are the warehouses of the turn of the century that often come to the minds of people who do not have relatives in institutions. As parents, we could never place our children in warehouses.

Federal Medicaid funds and standards have played a major role in the dramatic improvement in the quality of institutions. My son lives on a brightly colored unit with 12 other residents and sleeps in a room with two other children. He goes out into the community for school each day and when he returns to the institution, he has training programs for eating, walking, dressing and toileting, among others. The staff is generally caring, committed and creative.

Tighter enforcement of existing Medicaid standards or adoption of even tougher standards, such as those presently being considered by the Department of Health and Human Services, could make our children's residences even better places.

To say that institutions have come a long way from the olden days is not to say that all abuses have been eliminated. There are still some instances of improper care and even violence in institutions—and every possible effort should be taken to root out these problems.

To be fair, however, one must recognize that these same problems exist in society as a whole and even in community living arrangements. For example, a series of articles in the summer of 1983, copies of which are attached for inclusion in the hearing record, recount how 16 residents of an institution who

were moved into newly built group homes in Florida died soon after they were moved. The reasons for their deaths vary from improper nursing and medical care to "transfer trauma," a medical theory that some people lose the will to live after being taken from familiar surroundings. As a result of these unnecessary deaths, further transfers were halted.

I do not cite this example to suggest that these problems are rampant in community living arrangements, any more than similar anecdotal information demonstrates widespread problems in institutions. There is no comprehensive data to prove either case. The key point is that protection of the handicapped --in and out of institutions-- is particularly crucial because most handicapped people are not capable of protecting themselves.

In short, we do not maintain that institutions are perfect residences nor that all of them are run as well as we'd like to see them run. But we do know from first hand experience that there are many well run institutions in all parts of the United States that provide significant benefits to our children. Under these circumstances, we think the advocates of legislation that would inevitably result in closing many, if not most, of our children's residences have an enormous responsibility to demonstrate that our children can be equally or better served in community-based residential facilities.

Group Homes and Related Community-based living Facilities for Severely to Profoundly Retarded Persons Are Still in an Experimental Stage

For the most part, group homes have been used for the mildly to moderately retarded who do not have severe medical or behavioral problems. We think their track record in serving this population indicates that most such people who now live in institutions can benefit from placements in community living facilities.

However, most residents of institutions today are not mildly or moderately

retarded. They cannot dress and feed themselves and hold jobs in the community. They are severely and profoundly retarded; people whose trainability is very limited and who need around-the-clock care.

The present population of institutions--where more than 76% of the residents are severely or profoundly retarded--reflects the success over the past decade of moving many mildly and moderately retarded people out of institutions into the community. Over the past 10 years, this movement has resulted in a 37% decline in the institutional population. At the same time, the residents who remain in institutions and those children and adults who have replaced some of the ones who moved into the community are far more retarded and multiply handicapped.

The number of severely and profoundly retarded persons in community-based facilities today is very small. The studies of how these people fare are few and inconclusive; and all the available evidence suggests that it is more a question of the way in which groups of individuals and staff are organized than the size of the residence. Pursuant to this concept, many of the larger institutions redesigned their larger wards into smaller units. Other factors such as geographical location, resident background, average age and the qualifications of the staff have been found to be more important in the development of the clients than the size of the facility.

The experience to date suggests that the concept that "bigness is bad" has no more truth when applied to the residences of the mentally retarded than it does to the size of corporations or universities. The experience to date would justify more experimentation with placing severely and profoundly retarded persons in community living arrangements, but it in no way would justify moving all such people into the community. What is needed is more experimentation and study; not more demagoguery. However appealing it is for people who do not have children in institutions to want to place our children in group homes

with white picket fences, the parents want proof-- empirical data, not articles of faith-- before we acquiesce in moving our children from environments in which they are doing well.

Existing Data on the Relative Costs of Institutions and Community Living Arrangements Are Contradictory and Inconclusive

The ARC has stated that cost studies demonstrate that for the same money we can serve two or three times as many mentally retarded persons in community living arrangements. Based in substantial part on this assumption, S. 2053 would increase the number of eligible recipients of Medicaid funds at least two to three hundred percent, and perhaps by as much as 700%.

Unfortunately, the cost studies do not support the basic premise. A fair reading of them shews that most are fatally flawed in conception. Many compare the costs of the typical resident of a group home - a mildly to moderately retarded individual-- with the typical resident of an institution, a severely to profoundly retarded person. In addition, many of the studies do not compare the same constellation of services. In short, for every study that says that group homes are cheaper, there is one that says that institutions cost less.

Where similar residents and services are compared, the costs appear to be about the same. In Northern Virginia, for example, several intermediate care facilities for the mentally retarded-- which house 8 to 10 severely to profoundly retarded persons apiece, including some who have been discharged from the nearby institution--have found that their actual costs of care exceed the per diem costs at the institution.

The question of costs is an important issue. What is needed here is for proponents and opponents of the different living arrangements to sit down together and agree upon a proper methodology-- perhaps with some prodding and funding from the Congress-- and then hire an independent consultant to assess

the real costs of caring for the severely and profoundly retarded in institutions and community living arrangements.

If S. 2053 Would "Guarantee" the Quality of Care for People Who Are Now Residents of Institutions, Why Are the Parents So Opposed?

Many parents fought long and hard to establish regional training centers so that their children could live in a quality residential environment close to them. Parents who have lived through all the difficulties and uncertainties of having handicapped children are particularly anxious to make sure their children will reside in a quality facility for the rest of their lives. To suggest that the certainty of good care that now exists will be replaced by an uncertain scheme is very threatening. In short, parents nationwide are pleased with the present situation and see no reason to trade it in for a system that at best might provide the same quality and at worst might have disastrous consequences,

Presently, our children live in places with substantial resources on hand—people experienced in how best to deal with a broad range of behavioral problems, including aggression, property destruction, self-injury, etc., and who are well grounded in current state-of-the-art technology, expertise not immediately available in a small community-based residential setting. In addition, our children have at hand the skilled services of physical and occupational therapists, social workers, doctors, nurses, dietitians, advocates and local human rights committees.

We have many questions about how our children would fare in community living arrangements. Would they have prompt access to all of these experts, or would they have to wait a week or a month until the experts could get to the house? We know how badly the local hospitals handle our children. Would there be small community facilities with doctors who understand their problems and needs? What would happen to people who have lived in institutions for decades? Is it really feasible to move them out without inflicting grievous harm?

What would happen to our kids when one of the staff was a bad apple?

Who else would be around to report that person? How would the facilities maintain the same kind of continuity that exists in institutions now when they had the kind of inevitable turnover that comes from burnout on the job and low financial rewards? Could Medicaid and other interested groups possibly monitor the quality of 20,000 community living arrangements as well as they presently monitor 260 institutions?

Finally, if group homes are to be opened up by definition to a potential universe of retarded citizens many times the size of those now receiving Medicaid funds-- with no criteria for choosing among applicants-- then the odds are great that many of our children will have no place to go when the states choose to close the institutions to save money. Or, if a state kept some of the institutions open, they would be far away from many of the parents and likely to be grossly underfunded. S. 2053 may say that any remaining institutions would have to maintain certain Medicaid standards, but when the financial crunch hits who is to say that those standards won't be reduced or laxly enforced?

Without criteria for admitting applicants into group homes, it is even possible that the bill might have the perverse effect of aiding mildly and moderately handicapped individuals to the detriment of the severely and profoundly retarded. This result could come to pass if states chose to serve the less retarded first in community living arrangements because they are less expensive to care for, i.e., they could serve more people for the same dollars.

We deeply empathize-- and we emphasize the word empathize-- with parents whose retarded children live at home. We have been there and we know how difficult it is. However, we know of no magic that can stretch the \$3 billion in Medicaid funds being spent on the most retarded children living in institutions to provide services for three to seven times that population. The hard data simply isn't there to demonstrate that we can serve even one more retarded person and maintain the present level of quality care by moving the retarded

into community living arrangements. The answer lies in more money and, until such time as the necessary funds are secured, a rational society always must devote its limited dollars to those people who are in the greatest need.

If S. 2053 Is Not Acceptable, What Can Be Done to Aid People Who Could Best Be Served in the Community, Whether They're Living in Institutions or at Home Presently?

The first answer is that more money is needed. There is no substitute for dollars. Realistically, with \$200 billion deficits facing the federal government for as far as the eye can see, there is not likely to be much help forthcoming from the federal government. Therefore, the states may be the places to look. Many of their economies have picked up and the necessary monies would appear smaller on a state-by-state basis. Moreover, it would avoid the potentially disastrous effects of imposing a national solution on the very different worlds that exist in different states.

Second, we must eliminate the bias in the Medicaid program that favors institutional funding. We believe the Congress made an impressive start in that direction with the Medicaid waiver program and we understand some 33 states have applied for waivers. That program should be expanded so that Medicaid funding is authorized for group homes on the same basis as it is for institutions.

Third, emphasis should be placed first on moving the mildly and moderate retarded, those without major physical or behavioral problems, out of the institutions and into group homes. These are the people everyone agrees are most capable of benefitting from living in the community.

Fourth, the role of the parents in caring for their children must continue to be respected. We love our kids and know more about them and what is best for them than all of the professionals in this field. Imagine how angry you would be if a teacher told you that you were raising your children incorrectly and that he or she-- the teacher-- was going to correct the problem.

And that teacher had the authority to do so. It is the height of arrogance and patronizing for people who are not in our situation to tell us that they know what is best for our children; that all we need to appreciate that they are correct is to be "educated."

Until there has been extensive experience in group homes with the many different kinds of children who are severely and. profoundly retarded and that experience has been quantified and evaluated and truly shown to provide better care for all our children, we will continue to support federal funding for our institutions. We must maintain a continuum of services from-private homes to group homes to institutions to assure that the particular needs of our children-- and not the needs of those with an ideological predisposition--are best served. 1