TESTIMONY OF

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TO THE

UNITED STATES SENATE
FINANCE COMMITTEE
SUBCOMMITTEE ON HEALTH

RE: S.2053
THE COMMUNITY AND FAMILY LIVING
AMENDMENTS OF 1983

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Senate Dirksen Building
Room 215
Washington, D.C.

My name is John Clarke. I reside at 6338 East Mississippi Street in Denver, Colorado. I am a licensed Ph.D. Clinical Psychologist and practice in my firm, Colorado Rehabilitation and Clinical Consultants. I am also the parent of a son, Roger, age 20 who resides in a Colorado state institution certified as an ICF-MR for the purpose of receiving federal medicaid funds at a current rate exceeding $100/day plus funds for his education.

During the past several years I have had a number of opportunities which most parents have not. I have traveled outside of Colorado to visit community services which have been recognized for being exemplary; in particular, a number of the programs outside of Philadelphia for persons who have left Pennhurst under court order, the Macomb-Oakland Regional Center in Michigan which has returned 1200 people from institutions to the community in 10 years and has not admitted anyone to an institution in the past 5 years, and Region V in Nebraska (Lincoln and surrounding communities). I have also been fortunate to attend a number of seminars and workshops in Colorado by "state of the art" practitioners such as the late Dr. Marc Gold, Dr. John McGee, Dr. Jerry Goff, Dr. Lou Brown and Karen Green and to visit several of the newly developed community programs in Colorado. All of these experiences have changed my views on services for persons with developmental disabilities. They have clearly demonstrated to me that anyone can have his/her needs appropriately met in the community. It is being done, it can be done and it must be done.

My observations are also consistent with the very compelling data seen in the longitudinal research over four years on the Pennhurst populations reported by Jim Conroy at Temple University and Valerie Bradley at HSRI, Boston. Their research, the most rigorous scientific design using matched samples or functional twins, clearly presents data that cannot be argued away by personal opinions and emotions. The results indicate that all individuals, regardless of severity of disability, continue to make significant developmental gains leading toward reduced dependency by living in home-like community settings. Unfortunately, their counterparts who have been left behind in the institution, at a reported cost of $165/day, are making no developmental gains; indeed, a painful indictment of Pennhurst, and perhaps large congregate care residences in general. Institutional environments are not conducive to individualized programming, growth and development.

The technological revolution of the past decade has been invigorating, yet I believe that it is but a glimpse of what the future holds in special education, vocational training, non-aversive behavioral psychology, physical/occupational therapy, adaptive equipment and bioengineering. What we know today - let alone what is yet to come - can make the future brighter for all persons with developmental disabilities and their families; however, incentives for states to continue funding institutions with medicaid funds could maintain the status quo and prevent this bright future and emancipation.

At this point I would like to share my personal perspective as it relates to my own son. Roger is now 20 years of age and has resided at the Wheatridge Regional Center for about 10 years. The decision to place him was extremely difficult for his mother and me. We did not select institutional placement as our first choice nor did any of the other parents I know who placed their children in Wheatridge. When my wife and I realized that we could not give our son the care and attention he needed, we could find no family support services nor program in the community that was right for him. Had community programs been available we would have placed him in a community program.

There have been substantial changes and new developments in recent years as I mentioned previously. If I could put myself in the shoes of younger parents with younger children I would clearly and unequivocally strive to keep my child at home with family support services or if necessary, place my child in a community living arrangment. There is no question in my mind that such alternatives are superior to institutional placement. I have never seen a program that is provided in the institution that cannot be provided in the community and which is usually done better. I am aware that good programs don't always exist in some communities and that the "state of the art" technology has not been replicated in all communities. It seems clear to me that Senate Bill 2053 provides the impetus to create such programs throughout the land and give them financial incentives and stability.

I am not advocating that institutions simply be closed. I do not want my son dumped into just any kind of program but I do want him to have the opportunity to benefit from the best technological developments, to live in a homelike setting and to participate in community life just like you and me - to experience success and failure, happiness and sadness and the dignity of personal identity. It is the job of parents such as myself to work with the agencies which have the responsibility for developing programs for persons with developmental disabilities to assure that a full array of quality services are developed in the community .

As a final comment I would like to note that my impressions of Roger's experiences at Wheatridge have been mixed. In general, he has been kindly treated and there are many good and dedicated staff members. On the other hand, his programming has been sporadic at best, particularly in the early years. There were long periods of time when he received very little, if any, meaningful programming. Only in the past two years has the situation changed and even then, the impetus came from outside the institution because of the passage of federal legislation (P.L. 94-142) and a Right to Education Lawsuit for Colorado children residing in institutions.

Roger is presently in an institution based school program and this experience has been generally positive; however, he has not had the kind of daily opportunities for social interaction and age appropriate peer modeling, which would be most desireable. He never sees anyone in a better state than he is. He has no opportunity to learn from role models who are not handicapped. Unfortunately, when he reaches age 21 it is quite uncertain whether he will be able to continue to receive adequate proramming. In other words, the programs developed at the institution came about as a result of outside pressures and may not continue when Roger "graduates" from school. Most of the adults residing at Ridge today get almost no developmental programming!

Right now we are at a critical stage of development for Roger and many other young adults. It is extremely timely and essential that the federal government shift its financial bias from institutions and congregate care to community program development so that these young people will have a chance to develop. You have heard and will continue to hear outcries from both parents who are losing the perceived security of the institution and the representatives of the industries we have created over the past thirteen years through the ICF-MR medicaid program. Listen to their concerns and provide the necessary safeguards to insure continuity of funds and services during the transition. However, I urge you to rise above the emotionalism and vested interests and provide the statesmanship and leadership for public policy which has been entrusted to you for the good of all of society. Ensuing generations should not have institutions forced upon them as it was upon us! We must provide the next generation with a better legacy. The future for children and adults with developmental disabilities is in your hands. I urge you to support S.2053.