### DEVELOPMENTAL DISABILITIES ACT EXTENSION AND RIGHTS OF MENTALLY RETARDED, 1973 HEARING

BEFORE THE

#### SUBCOMMITTEE ON THE HANDICAPPED

OF THE

#### COMMITTEE ON LABOR AND PUBLIC WELFARE UNITED STATES SENATE

**NINETY-THIRD CONGRESS** 

FIRST SESSION

ON

S. 427

TO PROVIDE FOR THE EXTENSION OF THE DEVELOPMENTAL DISABILITIES SERVICES AND FACILITIES CONSTRUCTION ACT

S. 458

TO PROVIDE FOR THE HUMANE CARE, TREATMENT, HABILITATION AND PROTECTION OF THE MENTALLY RETARDED IN RESIDENTIAL FACILITIES THROUGH THE ESTABLISHMENT OF STRICT QUALITY OPERATION AND CONTROL STANDARDS AND THE SUPPORT OF THE IMPLEMENTATION OF SUCH STANDARDS BY FEDERAL ASSISTANCE, TO ESTABLISH STATE PLANS WHICH REQUIRE A SURVEY OF NEED FOR ASSISTANCE TO RESIDENTIAL FACILITIES TO ENABLE THEM TO BE IN COMPLIANCE WITH SUCH STANDARDS, SEEK TO MINIMIZE INAPPROPRIATE ADMISSIONS TO RESIDENTIAL FACILITIES, AND DEVELOP STRATEGIES WHICH STIMULATE THE DEVELOPMENT OF REGIONAL AND COMMUNITY PROGRAMS FOR THE MENTALLY RETARDED WHICH INCLUDE THE INTEGRATION OF SUCH RESIDENTIAL FACILITIES, AND FOR OTHER PURPOSES FEBRARY 8, 1973

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# STATEMENT OF DONALD BARTLETTE, DIRECTOR, PROGRAM AND SOCIAL WORK SERVICE, OUTREACH COMMUNITY CENTER, MINNEAPOLIS, MINN.

In relation to extending the Developmental Disabilities Act, Cliff and I ... feel it is an excellent device for providing services that aren't available to those with developmental disabilities.... It emphasizes a more humanizing approach....The act also promotes the normalization concept of providing services to these individuals.

We do feel that a stronger emphasis be placed in the area of consumer Involvement.... Only as a result of listening to our clientele, many changes have been made that would never have been made had we not listened to the people.

Because of the thousands of persons living in residential facilities who are being treated inhumanely and unjustly, we feel this act surely promotes a normalizing, humane way of life for residents of such facilities.

STATEMENT OF CLIFFORD POETZ, APARTMENT LIVING PROGRAM RESIDENT, OUTREACH COMMUNITY CENTER, MINNEAPOLIS, MINN.; PRESIDENT, CLIENT COUNCIL; MEMBER AT LARGE, REGION 1, MINNESOTA YOUTH ASSOCIATION

**Senator JAVITS**. Do you feel that a "bill of rights," such as we are contemplating, should protect not only those classified as "mentally retarded" but also the "developmentally disabled."

**Mr. POETZ**. It should cover everybody under that label. I feel that would do a lot more good. In order to make it work, there should be standards set by Congress to say, "Here, you meet these standards before any money is given out through regional councils."

**Senator JAVTTS.** I gather you join Mr. Bartlette in the feeling about consumer satisfaction?

**Mr. POETZ**. Very strongly. I would like to recommend that it be mandatory that a consumer be on the regional boards. We have been sitting here all day, listening to parents who say, "Here, the retarded shouldn't be put under mandatory regulations because the parents feel that they can be more objective." I don't buy that one bit. The money is going to [a]ffect us and, as you know, as soon as it leaves Washington, it can disappear into a program and you can't find where it went. If we can't have some idea of where the money is going, it won't do one bit of good. I think that a consumer should be mandatory on these regional committees no matter who says what, because we have a bigger stake in it than anybody else does.

**Senator JAVITS.** I can understand why Mr. Bartlette said you were the most important witness we have today. Thank you very much for your testimony. It appeals to me very deeply.

## STATEMENT OF DENNIS E. HAGGERTY, ESQ., MEMBER, NATIONAL ADVISORY COUNCIL ON DEVELOPMENTAL DISABILITIES

This bill represents legislation whose time has come. Just as a Bill of Rights for citizens was necessary after colonial oppression was experienced by our forefathers, so now is a bill of rights for the mentally retarded necessary. This latter group has experienced oppression including dehumanization, loss of liberty, sometimes loss of life for many years.

I speak to you today on Senate bill 458... as a parent who placed his child in an institution... and watched as his will to exist seemed lost...and experienced the frustrations when unable to match conduct of institutional personnel against a norm in order to demand accountability.

This failure to hold people accountable for conduct where standards did not exist was the reason for opting for a class action suit to establish the right to education.

The proposals contained in Senate bill 458 would provide for the humane care, treatment, and habilitation of individuals with developmental disabilities in residential facilities through the establishment of quality standards

In recent years, public attention has focused on the conditions which existed in a number of State residential treatment facilities.... The publicity generated by these developments, that is investigations and litigation, has awakened the public to the need for immediate drastic improvements in all our States providing services to children and adults.