

**REAUTHORIZATION OF DISABILITY-RELATED  
PROGRAMS**

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**HEARING**

**BEFORE THE  
SUBCOMMITTEE ON DISABILITY POLICY  
OF THE**

**COMMITTEE ON  
LABOR AND HUMAN RESOURCES  
UNITED STATES SENATE**

**ONE HUNDRED THIRD CONGRESS**

**FIRST SESSION**

**ON**

**EXAMINING PROPOSED LEGISLATION TO AUTHORIZE FUNDS FOR PRO-  
GRAMS OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND  
BILL OF RIGHTS ACT, AND THE TECHNOLOGY-RELATED ASSISTANCE  
FOR INDIVIDUALS WITH DISABILITIES ACT**

**JUNE 29, 1993**

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# REAUTHORIZATION OF DISABILITY-RELATED PROGRAMS

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TUESDAY, JUNE 29, 1993

U.S. SENATE,  
SUBCOMMITTEE ON DISABILITY POLICY, OF THE COMMITTEE  
ON LABOR AND HUMAN RESOURCES,  
Washington, DC.

The subcommittee met, pursuant to notice, at 9:08 a.m., in room SD-430, Dirksen Senate Office Building, Senator Tom Harkin (chairman of the subcommittee) presiding.

Present: Senators Harkin, Wellstone, Durenberger, and Jeffords.

## OPENING STATEMENT OF SENATOR HARKIN

Senator HARKIN. Good morning. The Subcommittee on Disability Policy will come to order.

Next month, we celebrate the 3rd anniversary of the passage of the Americans with Disabilities Act. We can all be proud of this landmark legislation, but obviously, our work is not done. We cannot rest until we have established a national disability policy that is based on the values and the precepts of the ADA—that is, empowerment, inclusion and independence.

In other words, we need a national disability policy based on the following principles: that individuals with disabilities are entitled to be treated with dignity and respect; that individuals with disabilities are entitled to make informed choices and decisions; that individuals with disabilities are entitled to live in their own homes and communities where they can be fully included in all aspects of American life and where they can make meaningful contributions to their families, community, State and Nation; and that individuals with disabilities and their families must be provided with the services and supports necessary to transform these goals into realities.

Last year we reauthorized the Rehabilitation Act of 1973, which contains two components of our national disability policy—vocational rehabilitation to provide people with disabilities with the necessary skills and support services to enable them to achieve their career goals, and independent living services to ensure that people with disabilities are empowered to control their own lives and be fully included in all aspects of our society.

It is my expectation that Congress will enact legislation this year that addresses the needs of persons with disabilities for affordable health care, including the elimination of exclusions for pre-existing conditions and for consumer-directed personal assistance services.

The purpose of this hearing today is to consider the reauthorization of two additional pieces of legislation that contain components of our national disability policy—the Technology-Related Assistance for Individuals with Disabilities Act of 1988, and the Developmental Disabilities Assistance and Bill of Rights Act.

For the past 6 months, my staff and Senator Durenberger's staff have been reviewing recommendations, developing proposals, and meeting with all interested parties in an effort to craft bipartisan consensus bills.

We have asked each of you to comment on the product of these efforts—documents that are referred to as "Staff discussion drafts." I look forward to hearing from all of our distinguished witnesses today.

In order to assure that we conclude on schedule, I would appreciate it if each of you would summarize and highlight the points that you wish to make to the subcommittee. We will make sure that each of your prepared statements is included in the record in its entirety, and again, if you could please summarize your testimony to only the most salient and most important things you want us to remember and want us to focus on.

[The prepared statement of Senator Harkin follows:]

#### PREPARED STATEMENT OF SENATOR HARKIN

Next month we celebrate the third anniversary of the passage of the Americans with Disabilities Act. We can all be proud of this landmark legislation, but obviously our work is not done. We cannot rest until we have established a national disability policy that is based on the values and precepts of the ADA: empowerment, inclusion, and independence.

In other words, we need a national disability policy based on the following principles:

- that individuals with disabilities are entitled to be treated with dignity and respect;
- that individuals with disabilities are entitled to make informed choices and decisions;
- that individuals with disabilities are entitled to live in their own homes and communities where they can be fully included in all aspects of American life and make meaningful contributions to their families, community, State and Nation;
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The purpose of this hearing is to consider the reauthorization of two additional pieces of legislation that contain components of our national-disability policy—The Technology-Related Assistance for Individuals with Disabilities Act of 1988 and the Developmental Disabilities Assistance and Bill of Rights Act.

The Tech Act provides financial assistance to States for the development and implementation of consumer-responsive, comprehensive statewide programs of technology-related assistance for individuals of all ages with disabilities through systemic change and advocacy activities.

The Tech Act is designed to provide increased access to and funding for a category of tools that some persons with disabilities need in order to be fully included in American society—assistive technology devices and assistive technology services. Assistive technology devices are devices used by persons with disabilities to assist them in performing an activity that a nondisabled person can perform without the device. Examples of such devices include such “high-tech” devices as voice activated computers, talking communication devices, automatic page turners, or breath activated switches and such “low-tech” devices as an easy-to-turn door handles or wheelchair ramps.

While the ADA opens the doors of opportunity for people with disabilities, there is still a need to provide access to and funding for assistive technology so that these individuals can control their own lives and be fully included in all aspects of our society.

I believe the reauthorization of the Tech Act must focus on the following themes:

1. Ensuring the Federal support necessary to allow the States to successfully complete the systemic change process begun under the Technology-Related Assistance Act of 1988;

2. Clarifying that the focus of the State projects should be on systemic change and advocacy activities;

3. Promoting systemic change through individual advocacy by ensuring that individuals with disabilities have access to protection and advocacy services to secure their rights to assistive technology devices and assistive technology services;

4. Emphasizing the importance of consumer involvement in all aspects of the program;

5. Authorizing the necessary technical assistance on a national level to the State projects and to individuals with disabilities and other interested parties; and

6. Providing a basis for improved information systems and data collection on assistive technology through the development of a national classification system.

The second part of our hearing focuses on the Developmental Disabilities Assistance and Bill of Rights Act, (or the DD Act, for short).

The DD Act was passed over 20 years ago to assure that individuals with the most severe disabilities and their families have access to services. Today, the programs under the Act (support for State Developmental Disabilities Councils, Protection and Advocacy systems University Affiliated Programs, and projects of National Significance) are concerned with fostering state-of-the-art values and approaches that promote the independence and choice, produc-

tivity and contribution, integration and inclusion into the community, and empowerment of individuals with developmental disabilities and their families. Again, ADA opens the doors of opportunity. But in the case of people with severe disabilities, there is a need to assist and enable individuals and their families to access services, supports and other assistance so that they can control their own lives and be fully included in all aspects of society.

I believe that the reauthorization of the DD Act must be based on the following themes:

(1) Updating of the language and concepts in the Act to reflect new ways of thinking about people with disabilities, and to ensure that the language used in the Act is consistent with other Federal disability policy;

(2) Making organizational changes to make the Act easier to understand and more "user-friendly";

(3) Increasing flexibility and autonomy for Developmental Disabilities Councils and Protection and Advocacy Systems so that they are able to carry out their responsibilities;

(4) Increasing accountability and quality for all program components; and

(5) strengthening relationships with the larger disability community.

For the past 6 months, my staff and Senator Durenberger's staff have been reviewing recommendations, developing proposals, meeting with all interested parties in an effort to craft bipartisan consensus bills.

We have asked each of you to comment on the product of these efforts—documents that are referred to as "Staff Discussion Drafts." I look forward to hearing from all of our distinguished witnesses today.

For additional information, contact Linda Hinton or Ansley Bacon, Senate Subcommittee on Disability Policy, chaired by Senator Tom Harkin. The telephone number is (202) 224-6265.

Senator HARKIN. With that, we welcome our first panel—Dr. William Smith is acting assistant secretary, Office of Special Education and Rehabilitative Services. He is accompanied by Carol Cichowski, director of the Division of Special Education, Rehabilitation and Research Analysis, at the Office of Management and Budget, and Betty Jo Berland, planning and evaluation officer with the National Institute on Disability and Rehabilitation Research.

Dr. Smith, welcome to the subcommittee. Please proceed as you so desire.

**STATEMENTS OF DR. WILLIAM SMITH, ACTING ASSISTANT SECRETARY, OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES, ACCOMPANIED BY CAROL CICHOWSKI, DIRECTOR, DIVISION OF SPECIAL EDUCATION, REHABILITATION AND RESEARCH ANALYSIS, OFFICE OF MANAGEMENT AND BUDGET/CFO, AND BETTY JO BERLAND, PLANNING AND EVALUATION OFFICER, NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH**

Dr. SMITH. Thank you, Mr. Chairman.

I am very pleased to be here today to discuss the reauthorization of the Technology-Related Assistance for Individuals with Disabil-



ities Act, and I will try to summarize, since you have the full text to be published.

The "Tech Act," as it is called, is administered by the National Institute on Disability and Rehabilitation Research, NIDRR, one of the three components of the Office of Special Education and Rehabilitative Services in the Department of Education.

The purpose of the Tech Act is to provide support to States to develop and implement comprehensive, consumer-responsive, statewide systems of technology-related assistance for individuals with disabilities. In the first year, fiscal year 1989, the Congress appropriated \$5.1 million for initial grants to nine States. Since that time, the appropriation level has increased to over \$34 million for fiscal year 1993, and NIDRR has made grants to 42 States. NIDRR has sufficient funds to make awards to the remaining eight States, the District of Columbia, and Puerto Rico this fiscal year, assuming that they submit acceptable applications.

As you know, the statute permits the State grantees to select from a wide range of authorized activities. All of these grantees have certain common elements in their programs, such as information and referral systems that provide ready access to information about assistive technology resources and products.

All of the State projects also conduct extensive public awareness efforts to inform persons with disabilities, parents, advocates, service providers, employers, and the general public about the potential benefits of assistive technology.

The statute mandated that the Department conduct an evaluation of the program. A key finding was that the States had not yet succeeded fully in establishing comprehensive, consumer-responsive statewide systems to provide technology-related assistance to persons with disabilities.

The evaluator found that many States were not as consumer-responsive in the operation of the tech grants as they could have been. The contractor, RFI, found that the State projects have not been able to reach all segments of the population with disabilities. Traditionally, underserved groups remain difficult to reach.

As you know, the administration has been working closely with the committee during this reauthorization process. Our priorities for reauthorization include the following: Providing up to 5 years of additional Federal support for States that have completed their extension grants but, despite significant progress, need additional Federal funding to complete implementation of the statewide systems. Second, requiring all projects to focus on systems change activities to help ensure that the benefits of this program are long-term and significant. We recommend that States that wish to receive a grant be required to review and, as appropriate, modify laws, regulations, policies, practices, procedures, and organizational structures that affect access to, the provision of, and funding for assistive technology devices and services.

We further suggest that States be required to transmit to the Secretary a plan for systems change within 18 months after enactment of the reauthorization legislation, or with its application for an extension grant, whichever comes first.

We further recommend ensuring that individuals with disabilities are involved in meaningful ways in the planning, development, implementation and assessment of statewide systems.

We recommend that States be required to undertake activities, including outreach to underserved groups, and the consumer training to facilitate the development and implementation of a consumer responsive system.

We recommend strengthening advocacy and protection services. We believe that advocacy and protection services can be instrumental in effecting systems change and increasing the independence of individuals with disabilities.

We recommend increasing accountability by requiring annual reports that document specific progress in achieving systems change.

We recommend expanding the provision of technical assistance, information, and training to ensure that States are able to develop quality comprehensive, consumer-responsive statewide systems.

These are our primary recommendations, and we would hope they would be the basis for whatever discussion you would like us to have.

I certainly appreciate the opportunity to discuss this important program. The two persons who are with me have particular expertise, and with your permission with whatever questions you have, I would like to draw upon them to be sure that you have the best answer.

Thank you, Mr. Chairman.

[The prepared statement of Dr. Smith follows:]

#### PREPARED STATEMENT OF WILLIAM L. SMITH

Mr. Chairman and members of the committee, I am pleased to be here today to discuss the reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act of 1988 (Public Law 100-407). The "Tech Act," as it is called, is administered by the National Institute on Disability and Rehabilitation Research (NIDRR), one of the three components of the Office of Special Education and Rehabilitative Services (OSERS) in the Department of Education.

The purpose of the Tech Act is to provide support to States to develop and implement comprehensive, consumer-responsive, statewide systems of technology-related assistance for individuals with disabilities. Technology-related assistance includes assistive devices—such as wheelchairs or communications boards—and assistive technology services—such as evaluation, prescription, or fitting for a device and training in its use.

In its first year, fiscal year 1989, the Congress appropriated \$5.1 million for this program, with which the Department awarded initial grants to nine States—an average award of \$515,000—and a mandated technical assistance contract to provide information and technical expertise to the grantees and designated entities in other States.

Since that time, the appropriation level has increased to over \$34 million for fiscal year 1993, and NIDRR has made grants to 42 States. NJDRR has sufficient funds to make awards to the remaining eight States, the District of Columbia, and Puerto Rico this fiscal year, assuming that they submit acceptable applications.

The statute requires each Governor to designate an entity responsible for applying for and managing the State's grant. Of the current 42 grantees, 24 are administered by State Vocational Rehabilitation agencies. Other designated entities include other State agencies, universities, and independent commissions.

Grants to States are awarded on a competitive basis, using an independent peer review process. Every State had applied for a grant at least once in the program's first 4 years, and many made several applications. This indicates to us that individuals with disabilities and their families, as well as those who provide services to them, recognize that there are major benefits to be obtained through improving the provision of assistive technology. This is the main reason we believe the Tech Act should be reauthorized: to give all States sufficient opportunity to establish statewide systems as envisioned by the Act.

As you know, the statute permits the State grantees to select from a wide range of authorized activities. All of these grantees have certain common elements in their programs, such as information and referral systems that provide ready access to information about assistive technology resources and products.

All of the State projects also conduct extensive public awareness efforts to inform persons with disabilities, parents, advocates, service providers, employers, and the general public about the potential benefits of assistive technology. Grantees use such techniques as public service announcements, local access television, travelling exhibits, and targeted mailings to "spread the word" about AT—as it is called—to a broad audience. Consumer advisory boards, consumer training, and technology demonstration centers are other typical activities in the effort to create comprehensive, consumer-responsive, statewide systems.

States also have the opportunity to be innovative and to try unique approaches. For example, North Carolina and Maine have set up income-contingent loan programs. New York has equipment loan programs and recycling centers; Alaska and New Mexico have aggressive outreach programs to serve Native American groups that are typically underserved, while Massachusetts has targeted outreach to Hispanic, African-American, and Asian-American populations. Maine and Utah are using video disc training programs and televised training in creative ways. Mobile vans are used in Minnesota and Vermont to demonstrate assistive technology in remote and rural regions of those States.

The statute mandated that the Department conduct an evaluation of the program. This was done through a contract to the Research Triangle Institute of North Carolina (RTI), and the four-volume report was sent to Congress in April of this year. At the time of the evaluation, nine States were beginning their third year of operation, 14 their second year, and 11 had just received grants for their first year. Because these State programs were phased in year by year, we could not have as much data, particularly outcome data, as we would have liked at the time of the evaluation.

A key finding was that the States had not yet succeeded fully in establishing comprehensive, consumer-responsive, statewide systems to provide technology-related assistance to persons with disabilities. However, the report indicated there had been enough progress to suggest that, with additional time and Federal support, the States would be able to make significant improvements.

The RTI study indicated that the States have been most successful in raising awareness about the potential of assistive technology, but the lack of access to funds to purchase AT remains a significant obstacle to widespread use.

The study also found that States have not been focused uniformly on undertaking those systems change activities that hold the most promise of facilitating the implementation of a comprehensive statewide system.

The evaluator found that many States were not as "consumer-responsive" in the operation of the "Tech grants" as they could have been. For example, some States relied on having individuals with disabilities on advisory boards as their major consumer-responsiveness strategy. However, those individuals with disabilities often were staff members of the service delivery agencies that might have been targeted for change. In many cases, individuals with disabilities and their family members were not full participants in Advisory Boards due to their lack of experience and training for the decision-making role.

RTI found that the State projects have not been able to reach all segments of the population with disabilities. Traditionally underserved groups remain difficult to reach. The States reported that they had difficulty in reaching elderly persons with disabilities, persons in rural areas, and those who are not English-speaking. In the future, the program must have a strong emphasis on outreach to underserved groups, and we must provide more technical assistance to the States to help them achieve more comprehensive coverage.

RTI found that certain problems seemed to be related to the nature of the entity designated to administer the project. State agencies often were hampered by employment and acquisition policies in the States; universities, as well as some State agencies, were perceived as remote by consumers. It is important that the designated entity be responsive to consumers and be able to conduct effectively the activities of the grant.

As you know, the Administration has been working closely with the Committee during this reauthorization process. Our priorities for reauthorization include:

- Providing up to 5 years of additional Federal support for States that have completed their extension grants, but, despite significant progress, need additional Federal funding to complete implementation of their statewide systems. Because we believe that States will need less Federal support over the 5-year grant period as they complete the development and implementation of their statewide systems, we rec-

ommend that in the fourth year of the grant Federal support be no more than 80 percent of the amount a State received in the third year of the grant. In the fifth year, we recommend that Federal support be no more than 60 percent of the amount a State received in the third year of the grant.

- Requiring all projects to focus on systems change activities to help ensure that the benefits of this program are long-term and significant. We recommend that States that wish to receive a grant be required to review and, as appropriate, modify laws, regulations, policies, practices, procedures, and organizational structures that affect access to, the provision of, and funding for assistive technology devices and services. States should also be authorized to support a wide variety of activities to meet their individual needs. These activities should include alternative State-financed loan systems, demonstrations of assistive technology devices, partnerships that promote participation by business and industry in the development, demonstration, and distribution of assistive technology devices, support for the program-related expenses of individuals with disabilities involved in statewide system planning and implementation activities, and mechanisms for recycling assistive technology devices. We further suggest that States be required to transmit to the Secretary a plan for systems change.

- Ensuring that individuals with disabilities are involved in meaningful ways in the planning, development, implementation, and assessment of the statewide system and in decisions about the provision of assistive technology to individuals. We recommend that States be required to undertake activities, including outreach to underserved groups and consumer training, to facilitate the development and implementation of a consumer-responsive system. For example, States should be required to involve individuals with disabilities in the development of a grant application, the designation of the entity responsible for administration of the grant, and the planning, development, implementation, and assessment of the statewide system.

To ensure that the statewide system meets the needs of individuals with disabilities from underserved groups, we further recommend that States be required to include in their applications a description of how they will address the needs of these individuals.

- Strengthening advocacy and protection services. We believe that advocacy and protection services can be instrumental in effecting systems change and increasing the independence of individuals with disabilities.

- Increasing accountability by requiring annual reports that document specific progress in achieving systems change. States should be required to undertake annual assessments of their statewide systems to determine the extent to which the State's goals for systems change and consumer responsiveness have been achieved and the areas that need to be addressed in the next year. The progress reports should include, for example, information on the progress States have made in achieving their systems change plans; an analysis of the laws, regulations, policies, practices, procedures, and organizational structures the State has changed, attempted to change, or will attempt to change in the next grant year; a description of the policies and procedures implemented relating to the accessibility and provision of, and funding for, assistive technology devices and services; a description of interagency agreements developed and implemented; and a description of outreach activities.

- Expanding the provision of technical assistance, information, and training to ensure that States are able to develop quality comprehensive, consumer-responsive statewide systems. We suggest that funds be used for a wide variety of activities, including activities that provide effective strategies for carrying out systems change, models for providing outreach to individuals with disabilities in underserved groups, and training to improve the provision of assistive technology capacity, including the development, demonstration, dissemination, and evaluation of curricula and materials and methods regarding the provision of assistive technology.

Mr. Chairman, I appreciate this opportunity to discuss this important program with you and will be pleased to answer any questions.

Senator HARKIN. I appreciate that very much, Dr. Smith.

Again, in your own words, tell me why is it so important that we change the system.

Dr. SMITH. I think the primary reason is that the manner in which business is presently conducted for individuals with disabilities, and especially for persons who need technology assistance, isn't working. What we really need to do is look at what has been proposed by the Congress as new strategies for getting States to

take a more serious approach to the development of consumer responsiveness.

Those are the kinds of things that we think are the prime reasons why this legislation is extremely important.

Senator HARKIN. When you say it isn't working, in what regard is it not working—in terms of meeting certain goals?

Dr. SMITH. There is a great deal of difference from State to State with regard to what it is they are doing and how they are doing it. Responsiveness to new legislation allows the States to be able to plan and design a more appropriate way to deal with whatever the categories are that are in particular legislation. We are looking, I think, at new ways of doing business. Historically, there has not been advocacy, and there has not been client responsiveness as a part of the service delivery in our State agencies. We think that that is most appropriate, and for that reason really would like to see even more intensive efforts made with regard to how we can have States accountable for what they are doing.

Senator HARKIN. Let me just interrupt. I was involved in the genesis of this bill back in 1987-88—and also back in the mid-1970's when I was on the Science and Technology Committee in the House. We were then working on assistive technology devices, and our chairman at that time was Representative Teague from Texas, who personally used some assistive devices. I became quite interested in this issue at that time, which helped lead to this bill some years later.

But again, let's keep in mind the end goal we are trying to reach with the Technology Assistance Act. It is to provide, first of all, that a person with a disability can have the financial resources and access to the latest technology that will enable that person to be independent, having a meaningful life, to contribute to society, to work, to travel, to maintain himself or herself in his or her home. That is what we are working for.

Now, we need a system set up to make sure that this happens, that a person with a disability has access to and the resources necessary to acquire assistive technology.

Now, am I missing anything? I don't think so. We need to make sure that we have an advocacy system that will inform people who have disabilities of the technology that may be available. The advocacy system will need to do two things: One, alert them as to what is available and second, to advocate on their behalf to State agencies and the Federal Government to make sure that these devices get to them.

I was going to read from the bill, but I think what I've said summarizes the bill's intent. One aspect I did not mention is that consumers need to be the drivers of the system, so that if there is not a piece of technology out there that they need, someone will develop it because the demand will be out there for it.

Well, those are the purposes of the Act, and I don't need to read it all; you are more aware of it than I am. Again, back to changing the system and why we periodically review and reauthorize these bills. We ask: Are the purposes of the Act being fulfilled? I suppose, from my viewpoint, partially, but a lot of things have changed in the last 4 or 5 years, so we have changes to make in order to keep up with it.

First of all, I want to say thank you to you and your staff for all your help over the last several weeks. You have been a great help to our staff, and I believe that most of the points you made in your statement have been reflected in the bill.

Again, the primary purpose of the Act is to help States to bring about permanent systems change that is consumer-responsive, comprehensive, statewide, so that assistive technology devices are provided to individuals with disabilities. I wanted to State that before you went any further, because in the draft, we focused the projects on system change and advocacy.

Do you think the accountability mechanisms included in the draft will accomplish the goals that we have just stated here of systemic change, accountability mechanisms, and the priorities? Will the accountability mechanisms included in the draft accomplish these goals?

Dr. SMITH. Mr. Chairman, we think that many of the proposed progress reports, requirements, in the Senate staff draft will improve accountability. Particularly helpful are the requirements that each State describe successful systemic change and advocacy activities, including an analysis of the laws, regulations, policies, practices, and the processes that have changed.

We need to identify the projects that have tried to change or will attempt to change during the next grant period. We agree that this requirement will help States identify the legislation, the administrative and procedural changes needed in order to facilitate the accessibility, the provision and the funding of assistive technology devices and services as a first cut.

We think that the involvement of the State agencies in the development and implementation of the statewide system is extremely important. We believe, as the Senate bill suggests, that the success of the statewide system depends upon strong coordination among State agencies which can facilitate the provisions of assistive technology. In particular, we think that the requirement for States to describe the activities undertaken to enhance interagency coordination will help States identify all available resources for assistive technology. And in addition, giving individuals with disabilities and others who are interested parties an opportunity to comment on State actions is also a very good way of promoting accountability and a consumer-responsive system.

For example, we support requirements for seeking public comment on such matters as the development of the application. We are extremely concerned about the designation of the lead agency and the State actions regarding the planning, development, implementation and assessment of a statewide system.

It is quite clear that a development of a statewide system is the most important process so that those actions that you have described as ways of assisting people with disabilities can in fact take place.

When you asked the question why do we need a statewide system, in addition to where we want to go, the data show from the studies that this has been a slow process in our States. And one of the reasons that we have recommended the additional 5 years is that it is taking much longer than had been anticipated to get the States to begin to look at how they can be accountable for the

development of statewide systems. They are discovering that that is not an easy task. That is the real issue.

Now, let me just see if my colleagues have any comments.

Senator HARKIN. Yes, please go ahead.

Ms. Cichowski. You had asked earlier, Mr. Chairman, what needs to change in the system, and one thing that needs to change is that each State has a maze of programs and funding sources and rules and regulations relating to assistive technology, but it is a system that is not easy for a consumer who has a need for technology to access. In our view, it shouldn't require either research on the part of the consumer, or a lawyer, to get the technology the consumer needs to be more productive and independent and empowered, as you say.

So one of the things we are asking States to do under this program is to look at their laws and regulations and policies and procedures and identify those that set up barriers to consumers. A consumer ought to be able to get access in a timely manner and access to the technology that is appropriate. One of the problems we have is that providers and professionals in the system are also insufficiently informed and knowledgeable about the benefits of technologies.

So a lot of work needs to be done to enable the programs that we have in place to deliver technology more efficiently. Beyond that, States need to think about gaps in services that are not met by programs. But to start with, in our major delivery systems—special ed, vocational rehab, medical assistance—we aren't operating them in a way that is facilitating the provision of assistive technology.

Senator HARKIN. Very good. Did you have anything to add to that, Betty Jo?

Ms. BERLAND. I think there are a couple things that the systems need to focus on particularly for improvement. One is that there are people who continue to "fall through the cracks," people who are not necessarily eligible for services under some of the existing statutes, and those are people that, in order to be comprehensive, the States have to look at.

The other is that they have not yet solved the problem of reaching the hard-to-reach, the so-called underserved populations who may be minorities, the people who are not English-speaking, the elderly, and in many cases residents of rural areas. So to be comprehensive, we think that is an area of focus for the next phase of this project.

Senator HARKIN. Are you satisfied with the way our draft covers that?

Ms. BERLAND. Yes.

Senator HARKIN. Very good. Thank you.

I want to welcome my two friends and colleagues—Senator Durenberger, who is the ranking member of this subcommittee and who has helped a great deal, with his staff, in forming this draft; and also, Senator Jeffords, who was the House sponsor of the companion bill of the Technology Assistance Act of 1988. So he was the leader on the House side, and now he is over here helping us out.

I would recognize you for opening statements, questions, whatever you prefer.

Senator Durenberger.

OPENING STATEMENT OF SENATOR DURENBERGER

Senator DURENBERGER. Mr. Chairman, thank you. I have a full statement that I would like to be made part of the record, and I'll just very briefly welcome everyone here today to the hearing on these two very important pieces of legislation that are up for reauthorization and to compliment you and your staff for the way in which, once again, this year, you are approaching a very comprehensive markup on, in this case, the Technology-Related Assistance for Individuals with Disabilities Act, and the Developmental Disabilities Assistance and Bill of Rights Act.

I want to extend a special welcome to some folks from my home State of Minnesota who have travelled 1,000 miles to be here with us today. Rachel Esparza and her mom, Ann, are here from Mendota Heights. Rachel is in the 4th grade at Mendota Heights Elementary School and uses a computer to communicate with her classmates and teachers, and she is going to tell us about how technology has contributed to her life.

Sue Swenson is also here. Sue is a mom. She has an 11-year-old son named Charlie. Charlie has some very severe disabilities, and she is going to share with us her experience with the program, Partners in Policymaking, and how it has empowered her and her family to do their part to change the world and make it more inclusive for kids like Charlie and Rachel.

We have made a lot of progress in the disabilities area in recent years, but we all have a long way to go. The reauthorization of these two acts will move us closer to the goal of making disability policy more consumer-responsive.

It is my hope that some of the changes in the legislation will result in policy that is easy for consumers to understand and consistent with other legislation like the Americans with Disabilities Act, and responsive to special needs of special communities and special places like Minnesota.

I am pleased that there has been so much input to this legislation from people in the disability community. The best legislation, as the chairman knows only too well, is that which comes from and is responsive to the needs of individuals it is intended to serve; and second, which has strong bipartisan support, which has always been the case in this subcommittee and in this committee when we are dealing with public policy relating to people with disabilities.

I don't have any specific questions, Mr. Chairman. Thank you.

Senator HARKIN. Thank you, Senator Durenberger.

Senator Jeffords.

OPENING STATEMENT OF SENATOR JEFFORDS

Senator JEFFORDS. Thank you, Mr. Chairman.

It doesn't seem possible that 5 years have gone by since passage of this Act, but I am so pleased with the progress that has been made, and I will just make my entire statement a part of the record.

I would like to make a couple of comments. The work of the Assistive Technology Project in Vermont is a prime example of the



success of the Tech Act. In my mind, this success directly correlates with the programmatic flexibility of the Tech Act.

One of the purposes of this reauthorization is to emphasize system changes and advocacy activities. Assistive technology projects in Vermont and many other States are well on their way to systems change. The AT project in Vermont has expanded access to assistive technology to individuals with disabilities in every corner of the State with consumer-responsive activities including equipment training, advocacy, expanded alternative funding through loans, grants, and equipment recycling, information and referral services, eliminating barriers to obtaining assistive technology, and many others.

While I believe the reauthorization of the Tech Act is shaping up well, I do believe we must be mindful of innovative and successful State programs working to fulfill the purposes of this Act. To that end, we should be cautious so as not to add prescriptive language in the reauthorization.

Thank you, Mr. Chairman. It has been a pleasure working with you on these bills over the years. It is so rewarding. I don't think there is anything more rewarding that you and I have worked together on than this particular area of the law, and it is a pleasure to be here with you today.

[The prepared statement of Senator Jeffords follows:]

#### PREPARED STATEMENT OF SENATOR JEFFORDS

Thank you, Mr. Chairman. I am happy to be here this morning for a hearing on of the reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act, or "Tech Act," and the Developmental Disabilities Assistance and Bill of Rights Act, or "DD Act". (Unfortunately, I have another commitment in the Foreign Relations Committee which I must be present for.)

Although this hearing is on reauthorization of two very important pieces of legislation, I am particularly interested in the reauthorization of the Tech Act. In 1988, as the principal sponsor of the Tech Act in the House of Representatives, I believed that it was a landmark piece of legislation in advancing our Nation's disability policy. With your support, and that of many others in both chambers, the bill passed Congress with strong bipartisan backing and was signed into law by President Reagan.

What we envisioned then was an idea of providing grants to States to provide assistive technology devices and services to individuals with disabilities. That idea became a reality.

The availability of assistive technology leads to more mobility and independence in daily living for individuals with disabilities. It also translates into more freedom—freedom to do what one wants, when to do it, and how to do it. And technology doesn't have to cost a fortune. A small assistive device, such as a special door handle, however simple and low in cost, can change the life of a person with a disability. With a little technology assistance, simple tasks are no longer a formidable obstacle.

The work of the Assistive Technology Project in Vermont is a prime example of the success of the Tech Act. In my mind, this success directly correlates with the programmatic flexibility of the Tech Act.

One of the purposes of this reauthorization is to emphasize systems change and advocacy activities. Assistive Technology projects in Vermont and many other States are well on their way to systems change. The AT project in Vermont has expanded access to assistive technology to individuals with disabilities in every corner of the State with consumer-responsive activities including equipment training, advocacy, expanded alternative funding through loans, grants, and equipment recycling, information and referral services, eliminating barriers to obtaining assistive technology, and many others.

While I believe the reauthorization of the Tech Act is shaping up well, I do believe we must be mindful of innovative and successful State programs working to fulfill the purposes and spirit of this Act. To that end, we should be cautious so as not to add prescriptive language in the reauthorization. States must be allowed the flexibility needed to provide all individuals with disabilities with access to, and funding for, assistive technology devices and services depending on each State's particular circumstances.

I am hopeful that we can work out the minor differences with the bill by the time we get to the floor. I am sorry I can't stay to hear testimony from this morning's witnesses. However, I look forward to working with the Chairman to reach a solid bipartisan consensus on reauthorization of the Tech Act.

Senator HARKIN. Thank you very much, Senator Jeffords.

Actually, I love having Jim Jeffords on the Senate side—he is a real breath of fresh air—but I miss having him on the House side to take care of these things over there. It's a real pleasure to have you here Jim.

Just one last thing, Dr. Smith. I was interested to read in your written testimony that the evaluation mandated under the Act and conducted by the Research Triangle Institute found that "many States were not as consumer-responsive in the operation of the tech grants as they could have been."

Again, we sort of talked about this. Could you just give us some conception of what "consumer-responsive" ought to be?

Dr. SMITH. Yes, Mr. Chairman. The Department agrees with the Congress that consumer-responsiveness must be a primary attribute of any successful statewide system for assistive technology. We believe that at a minimum, such a system must have the following characteristics in order to be consumer-responsive.

First, the system must be accessible to individuals with disabilities and to their family members or representatives. We think it must be a user-friendly system.

Two, the system must respond to the need for assistive technology devices and assistive technology services in a timely manner, maximizing the extent to which individuals with disabilities receive appropriate devices and services.

And finally, the system must provide for the maximum possible participation and inclusion of individuals with disabilities, or their families or representatives where appropriate, in decisions concerning their individual technology and its use, as well as participation in the planning, development, implementation and assessment of the statewide system.

We think that those characteristics really would help develop a consumer-responsive environment.

Senator HARKIN. Dr. Smith, thank you very much.

Did either of you have anything else to add before we move on, Carol, Betty Jo?

Ms. Cichowski. No, Senator.

Ms. BERLAND. No, Senator.

Senator HARKIN. Thank you all very much.

Thank you, Dr. Smith, and again, thanks for all of your help in getting the draft ready.

Dr. SMITH. Thank you very much, Senator.

Senator HARKIN. Our second panel will be Rachel Esparza from Mendota Heights, MN, accompanied by her mother Ann Esparza; and Casey Hayse, from Iowa City, IA.

Ann and Rachel Esparza are testifying as consumers. Rachel, who has cerebral palsy, is 11 years old and uses an augmentative communication device and a power wheelchair.

Casey Hayse is testifying as a consumer who has been involved in the development and implementation of the Consumer-Responsive Program of Technology-Related Assistance in Iowa. Casey, who has cerebral palsy, uses assistive technology. She is trained in social work and has served as a staff member at an independent living center in Illinois.

We'll start first with Ann and Rachel, whenever you are ready to go. Welcome to the subcommittee.

**STATEMENTS OF RACHEL ESPARZA, MENDOTA HEIGHTS, MN,  
ACCOMPANIED BY HER MOTHER, ANN ESPARZA; AND CASEY  
HAYSE, IOWA CITY, IA**

Mrs. ESPARZA. Honorable Senator Harkin, Senator Durenberger, distinguished panelists and guests, my name is Ann Esparza, and as Senator Durenberger pointed out, I live in Mendota Heights, MN.

My daughter Rachel would like to share with you some of the ways that technology has contributed to her life, and she will be using a communication device that sometimes functions and sometimes does not.

Senator HARKIN. Are you saying we need better technology?

Mrs. ESPARZA. More money to buy the better technology would help.

Senator HARKIN. Rachel.

Miss ESPARZA. Hi. My name is Rachel Esparza. I am 9 years old and will be in 4th grade next year. At school and at home, I use a computer with a special keyboard to do all my work and to play games with my friends. I usually drive a powered wheelchair. I have special switches that turn on lights for me and help me cook with my Mom. I have a van with a lift that takes me to T-ball, swimming, and horseback riding. I have lots of other things, too, like braces, walkers, a special bathroom, and things to hold my books for me. Mom can tell you about the STAR program and how it has helped lots of people in Minnesota.

Thank you.

Senator HARKIN. Thank you, Rachel.

Mrs. ESPARZA. Our family has been involved with the STAR program since it started in Minnesota in 1989, and I would like to share some of my experiences, Rachel's experiences, and my husband's experiences with STAR.

Several scholarship programs are available to enable people with disabilities and family members to attend national conferences. We received a scholarship to attend the 1991 RESNA Conference in Kansas City, and while we were able to there, we were able to talk with vendors and practitioners about a wide variety of equipment and services that would improve Rachel's life. We purchased some devices while we were there.

One of the greatest finds for us was a walker that provides Rachel with the ability to walk independently. We would not have known about this and other items had we not received the scholarship and attended the conference.

STAR also provides scholarships to attend the international technology conference called "Closing the Gap." One hundred seventeen scholarships have been awarded to date with information then shared with other assistance and providers.

STAR annually awards grants to provide mobile outreach services and seed money to establish new technology programs. A review process is used where consumers evaluate all the applications and make recommendations for funding. The recommendations of the review panel have never been overturned by the Governor's advisory council in the 4 years that the grants have been awarded. I served on that review process and really enjoyed it and found it valuable to find out what was going on in other parts of the State.

To date, 28 projects have been funded, and over 11,000 consumers have been served by this aspect of the STAR program alone. As you know, funding of devices and services continues to be the biggest barrier to receiving technology-related assistance. But in Minnesota, we are making a start.

I served as a member of a consumer task force on private reimbursement of assistive technology, and part of this experience was meeting face-to-face with insurance company reps and discussing common forms for prior authorization. The insurance companies are now participating in mutual education forums on various aspects of assistive technology.

Rachel and I testified before the Minnesota State Legislature to ensure that assistive technology is considered in Minnesota's own health care access legislation.

STAR also provides training on how to access services and provides support for existing and new agencies. A full-time specialist is available to help individuals and professionals throughout our State. STAR has published a funding directory for access to resources in Minnesota.

Recently, STAR began a program in cooperation with the Minnesota Disability Law Center to better inform individuals on their right of appeal in funding decisions as well as to provide technical assistance in the appeal process.

I understand that the proposed reauthorization of the Tech Act mandates that money go to protection and advocacy agencies. We feel that mandating one agency to provide those services goes against the purpose of the Act in letting consumers be the drivers

of the system. We are in favor, however, of those proposals that allow the States the greatest amount of flexibility in designing advocacy services to meet the needs of people with disabilities in their States.

Thank you for the opportunity to present my views to you. I encourage you to reauthorize the Tech Act so that STAR and other programs like it can continue to change the way people with disabilities access technology-related devices and services.

Rachel and I will be happy to answer any questions that you have. Rachel will answer easier if it is presented in a yes/no fashion.

Thank you.

[The joint prepared statement of Ann and Rachel Esparza follows:]

#### JOINT PREPARED OF ANN AND RACHEL ESPARZA

Honorable Senator Harkin, Senator Durenberger, distinguished panelists and guests, My name is Ann Esparza, thank you for the opportunity to be here today. I live in Mendota Heights, Minnesota with my husband, Joe, and my daughter, Rachel, who is with me today. Rachel would like to share with you some of the ways that technology has contributed to her life. Rachel will be aided by an augmentative communication device that she has used over the past 6 years.

Hi, My name is Rachel Marie Esparza. I am 9 years old and will be in fourth grade at Mendota School next year. I use lots of technology every day. At school I use a computer with a special keyboard. I do all my work on it. At home I use a computer to do my homework and to play games with my friends. I usually drive a powered wheelchair but I couldn't take it on the plane with me. I have special switches that turn on lights and that help me cook with my Mom. I go places in a van with a lift on it. Without my van, I couldn't go to T-ball or my swimming and horseback riding lessons. I have lots of other things too, like braces for my hands and feet, walkers, a special bathroom, and things to hold my books so I can read. Mom can tell you about my other stuff and about the STAR Program and how it's helped lots of people in Minnesota. Thank you.

[Ann]. Our family has been involved with the STAR Program since it started in Minnesota in 1989. I would like to share some of my experiences with the STAR Program.

#### CONSUMER INVOLVEMENT

People with disabilities have been involved in every aspect of the STAR Program. STAR has several scholarship programs that enable people with disabilities and family members to attend national conferences. STAR provided a scholarship so our family could attend the 1991 RESNA Conference in Kansas City. While there we were able to talk with vendors and practitioners about a wide variety of equipment and services that could improve Rachel's life. In fact, we even purchased some devices while we were there—items that we had either never seen before or only seen in catalogs. Our great find was a walker that provides Rachel with the support and protection necessary for her to walk independently. The vendor helped strap Rachel into the walker, and as dozens of people watched—and some took videotapes—Rachel took off on her own. Since she wasn't accustomed to the walker, she didn't quite walk, but hopped instead, from one end of the exhibit hall to the other. Never have I seen a happier little girl. We purchased the walker and negotiated with a local hospital that was attending the conference, to transport it home for us. Ever since, Rachel has been experiencing cardiovascular benefits from standing and walking in her walker and we've been experiencing the joy in her independence. While there, we also purchased item that help Rachel hold pencils and crayons. These same items also hold suckers and popsicles so she can now share some of the same treats as her friends without having Mom attached to the other end. We would not have known about these items if we had not received the STAR scholarship and attended the conference.

In addition to the RESNA conference, STAR also provides scholarships for people to attend the international technology conference called Closing the Gap, which is held in the Twin Cities each year. To date, STAR has provided scholarships to 117

consumers and family members who have then shared the information and their skills with other consumers, family members and providers.

More importantly, however, is the way that STAR involves consumers in the decisions that are made regarding how funds are distributed for service delivery.

STAR annually awards grants to provide mobile outreach services to individuals throughout Minnesota and also provides seed money to establish technology programs in various Communities. A consumer review process is used in which consumers evaluate all applications and make recommendations to the Governor's Advisory Council on Technology for People with Disabilities for funding. The recommendations of the review panel have never been overturned by the Governor's advisory Council in the 4 years the grants have been awarded.

Some examples of the programs that have been recommended by the review panel and have substantially impacted consumer choice in Minnesota, include funding a start-up habilitation technology lab to provide mobile outreach as well as a more established program; a Minnesota-based international disability-specific bulletin board that is also connected with the Department of Jobs and Training to help individuals with disabilities find jobs; a program to help farmers with disabilities (the predecessor of the Minnesota Agribility Project); an equipment loan program; an instructional program to help blind diabetics independently monitor their insulin; and, many more. Since 1989, 28 projects have been funded and over 11,000 consumers have been served by this aspect of the STAR Program alone.

#### SYSTEMS CHANGE

As you know, funding of devices and services continues to be the biggest barrier to receiving technology-related assistance for people with disabilities—but in Minnesota, we are making a start toward impacting that system. STAR convened a consumer task force on private reimbursement of assistive technology and I served as a member. The most useful part of this experience was meeting face-to-face with insurance company representatives and discussing common forms for prior authorization. While the process did not go as far as we would have liked, insurance companies are now participating in mutual education forums on various areas of assistive technology such as powered mobility, and augmentative communication.

Rachel and I also testified before the Minnesota State Legislature to ensure that assistive technology is considered as part of durable medical equipment in Minnesota's own health care access legislation. STAR has actively helped us find ways for consumers to be heard.

#### ADVOCACY

STAR has viewed self-advocacy as the most important tool available to individuals with disabilities and has implemented services and programs with that in mind. All materials provide consumers with information to make choices about devices and services. STAR also provides training on how to access those services and provides support for existing and new agencies. In addition a full time funding specialist assists individuals and professionals throughout our State and has produced a funding directory for access to resources in Minnesota. Recently, STAR began a program in cooperation with the Minnesota Disability Law Center to better inform individuals on their right to appeal the decisions of funders as well as provide technical assistance in the appeals process.

I understand that the proposed reauthorization of the Tech Act mandates that money go to protection and advocacy agencies.

In Minnesota, there are a variety of agencies that provide advocacy for people with disabilities. We feel that mandating one agency to provide those services goes against the purpose of this act, in letting the consumers be the drivers of the system. We would be in favor of those proposals that allow states the greatest amount of flexibility in designing advocacy services to meet the needs of people with disabilities in their States. I am particularly concerned that by locating funds in one area, the end result would be discrimination among disabilities themselves and become self-serving. Having used various advocacy services over the past 9 plus years, I have learned that each advocacy group has its own speciality, and as a consumer I would rather work with a number of "specialists" than a single, or a few "generalists".

I will be happy to answer any questions that you might have, and Rachel will as well as if formed as a "yes/no" question.

Thank you for the opportunity to present my views to you. I strongly encourage you to reauthorize the Tech Act so that STAR and programs like it can continue to change the way people with disabilities access technology related devices and services.

Senator HARKIN. Thank you very much, Ann and Rachel.

First off, it seems from your testimony that you have been very satisfied with the operation of the STAR program in Minnesota; is that right?

Mrs. ESPARZA. Absolutely.

Senator HARKIN. Do you feel, Rachel, that the STAR program has really helped you?

Miss Esparza. Yes.

Senator HARKIN. And have they listened to you? Have they listened to what you want?

Miss Esparza. Yes.

Senator HARKIN. It sounds like you have a good system in Minnesota.

I'll yield to my distinguished colleague from Minnesota, Senator Durenberger.

Senator DURENBERGER. Thanks. I just appreciate the opportunity to have this experience with Rachel and Ann. It is fund to have you in Washington, DC, Rachel. You can stay as long as you want—or as long as your mom lets you.

Mrs. ESPARZA. That might have been the wrong thing to say. [Laughter.]

Senator DURENBERGER. You referred to the off-again, on-again performance of equipment and things like that. Help us understand what are some of the—I guess I'd call them maybe the less expensive barriers to access to something that would satisfy a realistic need in Rachel's life and in your life. We sit here, trying to legislate for the whole country and for a variety of people, and you can never quite make the system be as personally responsive as it needs to be. And I think one of the reasons is the accountability system—I mean, we want to make sure that when we declare something to be the objective of policy, and we invest some resources, financial and otherwise, in doing it, that it actually happens, and so we get caught up in a variety of accountability measures. And I know with regard to both of these acts we have before us and many other things we do here, the whole issue of accountability—how do we make sure that what should happen actually happens, and we get some good outcomes and good results from it—and we tend sometimes to complicate the accountability side more than we need to.

I wonder if you could help us understand a little bit better how we can make systems like this more consumer-appropriate or person-appropriate and, at the same time, have the confidence that the objectives for which we set up this policy are being met and that the investments we are making in it are appropriately responsive to need.

Mrs. ESPARZA. Senator Durenberger, many times, information is provided to families at the onset of a birth injury or an injury later in life. That information needs to be an ongoing process. The groups are out there, and they give you the information one time, and they go away. Then, a few years down the line, when someone comes back and says they don't know about this, the response is typically: Well, we told you about this. When? It is usually at a time when crisis are most in crisis that they first learn about services. So we need to find a way to make sure that education of fami-

lies and consumers is ongoing. That is probably one of the biggest barriers.

Another barrier that we have encountered is time. Learning about services has been in the past left to families. Services and equipment—that has been left to families. And for persons who need to work, that's almost impossible. You try, and you do it on your lunch hour, and you try and try, and then you give up. Then you have to rely on outside people. Those persons on the outside that you are relying on typically have a 9 to 5 job as well. The advocacy services that work for you are 9 to 5. We need to find a way to expand those.

We need to find ways to break down the insurance barriers. Even talking to an insurance company is difficult on a 9 to 5 job. We need to educate insurance companies as to what assistive technology means to families; that it is not necessarily a large, very expensive piece of equipment as a powered wheelchair or communications device. It might be a \$25 switch that a family cannot afford, but absolutely needs.

Those are the barriers that we run into. I have found in Minnesota that we are pretty good. If you get connected in the beginning with an organization that will help you, you will always be connected to some organization. There is a lot of outreach.

But we still have a long way to go, and parents become frustrated and drop out of the system, and then it is no longer representative of how many people out there actually need the help; they have given up.

Senator DURENBERGER. You talked a little about your experiences both with health insurance and with Minnesota's efforts to try to make access to health care services more comprehensive. One of the difficult lines for the traditional system to draw is between medical services and what is sometimes called long-term care services, or functional disability services, or social services—a variety of things like that. I am not politically correct enough to use all the right terms, but I think you know what I am struggling with.

The traditional insurance companies in the health area are pretty good at getting you an orthopedist for a broken bone, or some kind of a primary care doctor to help you with a severe case of influenza, or detecting and remedying a virus. But the system, as I think you are pointing out, in many places just does not do a very good job on all of the other health-related services.

Do you have a specific suggestion or suggestions for us on how we might better deal with the second half of the services? In other words, if you can have a traditional insurance company taking care of the financial risk that is involved in the influenza, and in the broken bones and things like that, how might we as a society better deal with these other issues, the functional and quality of life-related issues?

Mrs. ESPARZA. I think, Senator, one of the quickest ways to solve that and solve some of the headaches for families and physicians is to have a standardized prior authorization process.

Typically, what happens is a family will get a denial with no explanation of the denial, other than that in your policy, this is not allowed. Then, when you want to appeal the decision, you have no



basis for appeal because you don't know exactly why they denied. It is very frustrating to the physician, because he is sending information back and forth and back and forth.

So if we could streamline the prior authorization time line and really stick to time limits, I know that there are time limits that the insurance companies have to respond in, but each time you send stuff back and forth, it can take a while.

Rachel's original powered wheelchair took us well over a year, and in some cases up to 3 years, depending on how we were in the funding process, to get it paid for. That was an out-of-pocket cash outlay. Her communications device took over a year. We paid out; then we appealed. The company eventually paid for it on their own rather than deal with the insurance.

Senator DURENBERGER. Obviously, if what we now call the insurance company and the medical services were partners in responding to your family's needs, it would probably change a whole lot, so that one can't point at the other and say it is not included, and somebody else says, "It is appropriate; I send them the bill"—and these excuses and lack of information going back and forth. But if they were partners, and they made a joint commitment to you, an annual commitment in exchange for which you give them a premium, that they are going to provide for those needs, they would be a lot more responsive. I think that's the direction the Clinton administration is trying to move this system in when they talk about accountable health plans and so forth. It would be to make all of these people partners in serving your needs so that it would be in their interest to be responsive to you, to sort of get ahead of the curve and try to bring to your attention information that you might not even have available to you, because it would help you, it would help Rachel, and it would help them at the same time.

Thank you, Mr. Chairman.

Senator HARKIN. Thank you, Senator Durenberger.

Senator Jeffords.

Senator JEFFORDS. I just want to say what a wonderful experience it has been to listen to you and see how Rachel is doing. It is just so rewarding to know the potential we have if we can get everyone to know what everyone else is doing and to spread the word and work together to improve things.

So I deeply appreciate your testimony, Rachel especially. Thank you.

Mrs. ESPARZA. I would like to add one other thing.

Senator JEFFORDS. Yes, please.

Mrs. ESPARZA. One other barrier within the insurance industry that we are experiencing right now is—Rachel needs a new communication device—obviously, it was double-talking. The insurance companies, in response to some of the concerns about medically necessary and educationally necessary, are writing out anything that could be considered educational, which immediately goes to communications devices. If we can find a way to address that, families would be better-served and we would be able to act proactively rather than reactively, which has typically been the case.

Thank you.

Senator JEFFORDS. Thank you.

Senator HARKIN. Good point.

Next, we'll turn to Casey Hayse. Casey, it is good to see you again. Welcome back. You are making Washington, DC your second home.

Ms. HAYSE. Des Moines and Washington, DC.

When I first visited the Capitol as a 12-year-old child with cerebral palsy, I never dreamed that I would be asked to testify at a Senate hearing about disability policies.

I have had various experiences working in the service system for people with disabilities. Based on my experiences providing services to and advocating for people with disabilities, I believe one of the most significant barriers faced by persons with disabilities is their attitude about themselves and their capabilities, engendered by their lack of access to appropriate assistive technology devices and services.

The attitude of many individuals with disabilities is formed and shaped by their lack of participation in society. This lack of participation is often due to lack of access to assistive technology.

In my work with the Iowa program, our systems change strategy had to be multifaceted and comprehensive. It had to include work on the State level to facilitate cooperation among agencies by sharing information and standardizing policies and procedures. On a local level, community service agencies not only need to learn about assistive technology services, but also must cooperate with each other to ensure that those services and resources are optimal.

But what about the constituency? The constituency of consumers of assistive technology must have skills and training in order to make informed choices and decisions about assistive technology devices and have knowledge about funding and how to acquire funding from those services.

Although the tech bill charged States with developing a consumer-responsive system of assistive technology services, a consumer-responsive system cannot occur without a large number of consumers not only being involved in the development of that system, but continually placing demands on the system for accountability and responsiveness. Consumers cannot place demands on the system or hold it accountable without being informed, educated and trained on assistive technology and other disability-related issues.

Our State does not have a foundation of strong, independent living centers for training and informing consumers. We have developed and are expanding the Iowa Consumer Empowerment Network, which will establish a core group of people with disabilities around the State who will be experts on assistive technology. We focused on self-advocacy and empowerment skills training, consumerism skills, how to pick out assistive technology, how to interact with vendors, and how to interact with service providers.

Also, funding—consumers learning how to locate funding sources, access funding for assistive technology devices, and use funding strategies for each funding source.

These experts will be qualified to provide peer support for other consumers and/or train groups of consumers and/or service providers on these issues.

The service delivery system and the bureaucracy that persons with disabilities must go through to acquire assistive technology is

very tedious, and often, people with disabilities get discouraged when their applications are turned down. We thought it would be very positive for families and consumers to have a resource of support when they start that process.

In order for the goals to be realized and sustained over time, we need systems change. Systems change must be recognized and defined as involving informed consumers at all levels and in all capacities. I know in the definition in the draft that I saw, "systemic change" was defined as "coordination and interagency agreements and collaboration," but no mention of consumers in that definition. I feel that it is very important to include consumers in all levels of program development.

The Consumer Empowerment Network initiative that we started to achieve a consumer-responsive system in our State was difficult. It was difficult to figure out what a consumer-responsive system meant. We are very happy to see a definition of "consumer-responsive"; this is necessary to give States the mandate to involve consumers in every part of their programs.

I would just like to tell you a couple of stories of people I know in Iowa who were helped by the Iowa Program for Assistive Technology. There was one individual from Sioux City who, at age 47, finally got a piece of augmentative communication equipment and last fall was able to be a presenter at a consumer training in Sioux City.

Senator HARKIN. Was it like Rachel's?

Ms. HAYSE. It was like Rachel's—but it worked. [Laughter.] How about that? Assistive technology is just like cars—sometimes they work, and sometimes they don't.

Senator HARKIN. That's true.

Ms. HAYSE. Except that car dealers are usually more helpful than some vendors of assistive technology, who don't always understand how important the joy is in being able to accomplish day-to-day tasks. Another person who attended consumer training was able to advocate for himself with the State Department of Vocational Rehabilitation so he could get attractive eyeglasses so he could go to job interviews, and later was able to learn how to drive with this advanced technology.

On a more personal note, I use assistive technology for performing job tasks and for walking my dog. I have a huge dog that likes to run very fast, and if I didn't have my scooter, he would be pulling me around on the ground, because he is strong enough to do that.

I recently found out that I could use my scooter on trails in Montana, and the trails that I was on were the same trails as grizzly bears. I saw grizzly bear tracks and cub tracks on my first day in Montana, and this scared me a lot. I was standing with my new husband in the middle of a beautiful clearing, and I saw a shadow far away. A woman came out from the shadows to us when the sun was going down, and she said, "You know, they have been spotting bear tracks around here." And I looked down on the ground, and they were all over. And I turned my scooter around as fast as I could and went as fast as I could back to the lodge. I decided that I could camp out in Iowa, and I would stay in the lodge in Montana.

Thank you. Are there any questions?  
 [The prepared statement of Ms. Hayse follows.]

PREPARED STATEMENT OF CASEY HAYSE

Mister Chairman, I consider it an honor and a privilege to be asked to speak before the Subcommittee on Disability Policy in our Nation's Capitol. Years ago, when I visited the Capitol as a twelve year old child with cerebral palsy, I never dreamed that I would be asked to testify at a Senate hearing about disability policy. My disability is very evident as I sit and speak before you, and I feel that it's appropriate to give you some of my own background and perspective as it pertains to Public Law 100-407; the Technology-Related Assistance for Persons with Disabilities Act.

I attended the University of Iowa and received my Masters degree in Social Work. I worked in Oak Park, IL as the Independent Living Skills Coordinator at the Progress Center for Independent Living, which serves suburban Cook County, IL. My advocacy work in Illinois included chairing the Community Education and Advocacy for Persons with Disability (CEAD) Committee which directed a pilot project funded by the Illinois University Affiliated Program on Developmental Disabilities (UAP) at the University of Illinois at Chicago, in cooperation with Community Support Services.

In addition, I served on the Illinois UAP Advisory Council; the steering committee for United Cerebral Palsy (UCP) of Greater Chicago, which determined the assistive technology services that would be provided in Cook County; and on the board of directors of the Illinois Partnership for Community Living. I was awarded the Susan S. Suter Award for State advocacy service for persons with disabilities, and I was the Illinois recipient of the Victory Award for personal achievement.

Based on my experiences providing services to and advocating for persons with disabilities, I believe one of the most significant barriers faced by persons with disabilities is their attitude about themselves and their capabilities, engendered by their lack of access to appropriate assistive technology devices and services. The attitude of many individuals with disabilities is informed and shaped by their lack of participation in society. This lack of participation is often due to lack of access to assistive technology.

I worked with individuals who acquired their first "real" mobility and communication devices. These individuals were able to be outside of their homes independently for the first time at the age of 40 or 50. These experiences as well as my own experiences increased my involvement with assistive technology issues and led me to my position with the Iowa Program for Assistive Technology (IPAT).

The Technology Related Assistance for Persons with Disabilities Act of 1988 (Tech Bill) is a monumental piece of legislation. It provides resources to States to develop their own programs and begin to change the assistive technology service systems within their State. The Iowa Program for Assistive Technology accepted this challenge with enthusiasm. As our work progressed, we began to realize that our time for accomplishing this change was short.

At the beginning of our project, we worked on identifying what the problems were in Iowa and determining what systems change had to occur. We developed a strategy to direct our efforts, and they should now ensure that the changes we create will remain long after IPAT has accomplished its goals.

We recognized that our system change strategy had to be multifaceted and comprehensive. It had to include work on the state level to facilitate cooperation among agencies, by sharing information and standardizing policies and procedures. On a local level, community service agencies not only need to learn about AT services, but also must cooperate with each other to ensure that those services and resources are optimal.

But what about the constituency? Most important, consumers of assistive technology must have skills and training in order to make informed choices and decisions about assistive technology devices, and have knowledge about funding sources and how to acquire funding from those sources. Although the Tech Bill charged states with developing a consumer responsive system of assistive technology services, consumer responsive was not defined in the legislation. We believe that a consumer responsive system cannot occur without a large number of consumers not only being involved in the development of that system, but continually placing demands on the system for accountability and responsiveness. Consumers cannot place demands on the system or hold it accountable—without being informed, educated, and trained on assistive technology and other disability related issues.

With my interactions with staff from other Tech projects, it became apparent to me that different States have developed different work plans to accomplish the goal of developing a comprehensive consumer-responsive system of assistive technology

services. Some States, like Utah for example, could use their network of Centers for Independent Living to offer training on assistive technology and create assistive technology equipment loan programs. Another State decided to buy a truck equipped with all types of assistive technology for staff to go into the communities and conduct assistive technology assessments and other services.

In some States, like our own, developing a consumer responsive system of assistive technology services requires an initiative of extensive consumer training that is statewide and consumer driven. I believe that one of the barriers that Iowa faces is that it has not developed a strong network of Independent Living Centers which provide consumer advocacy training.

This has created a situation in which Iowa does not have a large base of informed consumers with the skills and supports necessary to place the required demands on the service delivery system. IPAT does not have the foundation of Independent Living Centers to use as a vehicle for training and informing consumers. Consequently, IPAT has developed and is expanding the Iowa Consumer Empowerment Network, which established a core group of people with disabilities around the state who will be experts on assistive technology issues such as:

1. Self-advocacy and empowerment skills: consumers learning their rights under disability-related legislation such as the IDEA and the ADA; and consumers learning how to interact with assistive technology vendors and service providers;

2. Consumerism skills: consumers learning how to make informed choices about assistive technology equipment; and learning their rights and responsibilities as consumers of assistive technology;

3. Funding: consumers learning how to locate funding sources; access funding for assistive technology devices; use funding strategies for each funding source; to refer to legal advocates.

These experts will be qualified to provide peer support for other consumers, and/or train groups of consumers and/or service providers on these issues. Our grant will continue to support the Network and promote the individuals within the Network as experts on assistive technology issues to consumers, service providers, and policy makers.

Our State project believes that the goals articulated in the proposed addition of Section 2(a)(4)\* of the Act's Findings and Purposes are a necessary and important statement of the vision for consumers as full participants in our society. Our project also believes that in order for those goals to be realized and sustained over time that "systems change" must be recognized and defined as involving informed consumers at all levels and in all capacities of policy development.

As noted above, the Consumer Empowerment Network initiative undertaken by our grant project is a necessary part of creating a "consumer responsive" system in our State. The addition of a definition for "consumer responsive" under Section 3(4)\*\* is necessary to give States the mandate to involve consumers in every part of their program. In some states, like ours, this will also mean providing consumers with the knowledge and skills to be able to participate in every level of grant programming.

We are also supportive of the proposed changes with respect to advocacy and interagency coordination. [Sections 101(b)(2)\*\*\* and (3)\*\*\*\*]. As described above, our experience indicates that these are necessary activities for States to accomplish the goals of the Tech Bill.

Although we recognize the great importance of enhancing the ability of agencies and organizations to provide funding for assistive technology, we have concerns about labeling this process alone "systemic change"\*\*\*\*\*. We would encourage increased clarity of the concept of systems change to always include true consumer involvement and participation in that "systemic change" effort.

In addition, we believe that proposed Protection and Advocacy Alternative #2 is more effective than Alternative #1. Alternative #2, by not limiting the definition of a provider of protection and advocacy services, recognizes that protection and advocacy services, as defined in the Act, are services that many State projects are involved with as part of their systems change initiatives.

For example, in Iowa, we are involved with extensive consumer training with respect to all issues involving assistive technology, particularly, advocacy and funding. Our training initiatives involve consumers in all levels of program development and implementation. We believe our project has a more defined vision than other State agencies of how consumer involvement in technology issues is fundamental to sustainable systems change.

We also recognize that effective legal advocacy is an important part of ongoing systems change. Our grant project is involved in a contract with the University of Iowa Law School Legal Clinic to provide both legal representation for persons with disabilities with respect to assistive technology issues and to provide training to law

students with respect to these issues. This contract has the potential to create ongoing representation for persons with disabilities beyond the life of our grant project. There is potential for both ongoing representation by the Clinic and for increased numbers of lawyers in the State who are willing and able to represent the interests of persons with disabilities through either public interest work or private pro bono work.

Alternative #2 allows our State to continue the protection and advocacy services that we have undertaken. It is not clear that Alternative #1 would do so. Other States need to determine the best way to provide protection and advocacy services within their State's unique circumstances.

Now I would like to recount to you a few of the personal stories that have come from our grant activities. One individual who attended an IPAT training session was directed to investigate different types of technology to assist individuals with visual impairments. This individual discovered an advanced type of lens for eyeglasses which provided less distortion and better vision and depth perception. With help from IPAT, he developed a strategy to access funding for these advanced eyeglasses through the Iowa Department of Vocational Rehabilitation. After acquiring funding for these glasses, he searched for a vendor who was responsive to his needs for having glasses that were not only functional, but durable as well as attractive.

As a result of his improved vision and depth perception with the new glasses, he was able to acquire a driver's license for the first time at age 26. This experience not only vastly improved his quality of life, but allowed him to be a better consumer trainer because of the "real world" knowledge he had gained.

Another consumer who has cerebral palsy and uses an augmentative communication device shared his experience, frustration, and success in acquiring funding for his communication device as a consumer trainer for IPAT. For the first time, at age 46, he was able to be a presenter at a workshop in his community and will also be one of the consumer trainers at the Consumer Empowerment Network Training Conference in October.

As you can see, I use an electric scooter to allow me to have independent mobility. I can walk but walking takes a great deal of energy for me. I could not walk from the parking space outside to this hearing room without being out of breath and unable to speak. I also use this scooter in my business trips around Iowa, because it is light and easily transportable. This scooter helps me keep up with the staff in my office, because they're a fast-paced crew. If I did not have this scooter, I would be lost in the dust and always out of breath.

My scooter keeps me mobile at home, too. I use it to walk my Collie-Shepherd dog who is young and fast. I use the scooter to take evening walks in the park or to the Dairy Queen with my husband. Recently, I've learned that I can use my scooter in hiking trails. I was never able to fully experience the outdoors because I could not walk long distances, so it was a revelation for me to know that I can indeed go hiking with my scooter. I recently discovered that my scooter can go on the same trails that the Grizzly bears use in Montana. Immediately after this discovery, I zoomed toward the lodge to escape peril, and left my new husband running behind me. These experiences have inspired me to begin looking for a faster more rugged scooter to use outdoors.

**\*PROPOSED SEC. 2. FINDINGS AND PURPOSES (a)(4).** The goals of the Nation properly include providing individuals with disabilities with the tools, including assistive technology devices and assistive technology services, necessary to (A) make informed choices and decisions; and (B) achieve equality of opportunity, full inclusion and integration in society, employment, independent living, and economic and social self-sufficiency, for such individuals.

**\*\*PROPOSED SEC. 3(4). CONSUMER-RESPONSIVE.** The term "consumer-responsive" means (1) respect for individual dignity, personal responsibility, and self-determination, based on informed choice, of individuals with disabilities; (2) respect for the privacy, rights, and equal access (including the use of accessible formats), of the individuals; (3) the full participation and inclusion of the individuals, including involvement both individually and systemically in the identification, planning, use, delivery, and evaluation of assistive technology devices and assistive technology services; (4) support for the involvement of parents, family members, guardians, advocates, or authorized representatives if the individual with a disability requests, desires, or needs such involvement.

**\*\*\*PROPOSED SEC. 101 (b)(2). ADVOCACY.** The State may use funds for advocacy activities including (A) dissemination of information, training and technical assistance on funding and (B) individual case management or representing individuals with disabilities to secure their rights to assistive technology devices and assistive technology services.

\*\*\*\*PROPOSED SEC. 101 (b)(3). INTERAGENCY COORDINATION. The State may support activities (A) to identify and coordinate Federal and State policies, resources, and services relating to the provision of individuals with disabilities, including entering into interagency agreements; (B) to support the establishment or continuation of agencies and between the public sector and the private sector to facilitate the development and implementation of a consumer-responsive, comprehensive statewide program of technology-related assistance for individuals with disabilities; (C) to convene interagency work groups to enhance public funding options and coordinate access to funding for assistive technology devices and assistive technology services for individuals of all ages with disabilities with special attention to the issues of transition, home use and individual involvement in the identification, planning, use, delivery and evaluation of such devices and services or (D) to document and disseminate information about interagency activities that promote coordination of assistive technology services including evidence of increased participation of State and local special education, vocational rehabilitation and State medical assistance agencies and departments.

\*\*\*\*\*PROPOSED SEC. 3 (2)(10). SYSTEMIC CHANGE. The term "systemic change" means efforts that result in public and private agencies and organizations having greater capacity or enhanced ability to provide funding for or access to assistive technology devices and assistive technology services, or otherwise increase the availability of such technology, to benefit individuals with disabilities, the parents, family members, guardians, advocates, or authorized representatives of such individuals on a permanent bases.

Senator HARKIN. Casey, thank you very much for being here again today. I know you have been here before.

Is this your first time in Washington, Rachel?

Miss Esparza. Yes.

Senator HARKIN. Are you going to take a tour through the Capitol—or maybe you already have?

Mrs. ESPARZA. How much can we do in 3 or 4 hours?

Senator HARKIN. When did you get here?

Mrs. ESPARZA. Last night, in time for bed.

Senator HARKIN. And you're leaving this afternoon?

Mrs. ESPARZA. Yes.

Senator HARKIN. What time is your flight?

Mrs. ESPARZA. Six o'clock.

Senator HARKIN. Well, you have time. We will get you over there.

Ms. HAYSE. Yes. He is an excellent tour guide.

Senator HARKIN. I am glad you are here. Your testimony was great, but since this is your first time, you ought to get over to the Capitol we have an Office of Special Services there. Get over there and get a good tour through the Capitol today, and get into the Senate and the House and take a look at it. The Office of Special Services over there will help you get around.

Mrs. ESPARZA. Could we get a good map somewhere?

Senator HARKIN. I will have someone take you over there, OK? We will get one of these individuals in back of me to get you over there. You should do that.

Mrs. ESPARZA. Thank you.

Senator HARKIN. Casey, you heard Rachel's testimony and her mother Ann's testimony about the Minnesota system. Have you looked at that Minnesota system, or are you aware of it?

Ms. HAYSE. Yes.

Senator HARKIN. Is the Iowa system similar to that?

Ms. HAYSE. The Iowa system is a little bit different just because we have different issues. Iowa doesn't have a group of consumers that are strong and organized yet. Consumers in Iowa are aware of some issues, but not aware of all the political differences. There

are a lot of people spread out in Iowa, and they need to have support. And hopefully, the support network will help more people with disabilities to learn about AT and to be able to access funding with extra support.

Senator HARKIN. So you feel very strongly about this concept of being consumer-responsive.

Ms. HAYSE. I feel very strongly about systems being consumer-driven, and in our State, that is our goal when we are through, is to be a system of AT services that is driven by consumers.

Senator HARKIN. Can you give me some idea, Casey, of what percentage of Iowans with disabilities are aware of the Technology Assistance Act and understand that they have avenues open to them to receive this assistance?

Ms. HAYSE. I would say 30 to 40 percent.

Senator HARKIN. So not even half of them.

Ms. HAYSE. I think a lot of people are very spread out and that we need to reach deeper. And I think also, people with disabilities need to see other people with disabilities doing stuff. I think that's real important in our State, because there aren't a lot of leaders in our State who have disabilities.

Senator HARKIN. I have an idea I would like to bounce off you, if you will bear with me for a second. The Iowa communications network, this fiberoptic network that is being set up in Iowa, will be done by this fall. It will have an endpoint in every county. There will be one point in every county, and then it will go out from there. All the community colleges and universities will be hooked up. We are now trying to get the National Guard armories hooked up, and that type of thing. In a very short period, we will have two-way interactive communications in Iowa on this fiberoptic network.

I have been thinking about all the uses for this. Now, it is awfully hard for people with disabilities to travel.

Ms. HAYSE. Exactly.

Senator HARKIN. It is hard for them to go from Sioux City or someplace like that to Des Moines for a conference to be made aware of what is available; it is time consuming, difficult, and costs money—even from one county to another is very difficult.

So I am thinking about—and I challenge you to start thinking about—programs that we could develop early on this winter that would reach every one of those county seat towns, programs in which we would present to consumers what this bill does, what is available, and to get public input. Since the system is two-way interactive, we could have their input into the system. You might want to start thinking about that as a way of reaching that other 60 percent or so that are not being contacted.

Ms. HAYSE. I think that's a fantastic idea. You remember when I was here a few weeks ago, and you talked to me about this idea, and I thought it was really positive, because we could reach young adults with disabilities who are at the community colleges and at the universities, about what is available and what their rights are.

Senator HARKIN. Exactly. Well, let's think about developing that program.

Ms. HAYSE. OK.

Senator HARKIN. Whatever help we can give you, let us know, but obviously, you know it better than I do.



Ms. HAYSE. Well, Denita Swenson already promised me volunteers, so we're working together.

Senator HARKIN. All right. We will do it.

Ms. HAYSE. OK.

Senator HARKIN. Well, Ann, again, thank you very much for being here and sharing with us. It sounds like the Minnesota system is a great system, and much stronger on the consumer end than what I have seen in a lot of other States, which is really what we are trying to get through in this bill, is to really change the system and make it more consumer-responsive. So we will take a look at what you have done up in Minnesota.

Mrs. ESPARZA. We are happy with it.

Senator HARKIN. Thank you all very much for being here. It is good to see you again.

And I mean that—we are going to be here a couple more hours and have a lot more witnesses. You are obviously welcome to stay, and you can make your own decision, but if you would like to take Rachel over to the Capitol and get a tour, you ought to think about doing that. I thought maybe you had a couple more days here.

Mrs. ESPARZA. No. Minnesota is cheap in some ways. [Laughter.] Thank you, Senator.

Senator HARKIN. Thanks very much.

Senator HARKIN. Our next panel includes John Gannon, acting chair of the National Council on Disability, accompanied by Edward Burke, the chief governmental liaison; James Hardy, project director at the University of Iowa, Division of Developmental Disabilities, on behalf of the State Project Directors; Jenifer Simpson, policy associate, governmental activities, United Cerebral Palsy Associations, Incorporated, accompanied by Joshua Chartientz, on behalf of the Consortium for Citizens with Disabilities.

Good morning, everyone, and again, welcome. Is Joshua Chartientz here?

Ms. SIMPSON. He is back there misbehaving; he'll be down.

Senator HARKIN. OK. And everyone else is here. Again, welcome to the subcommittee. Your statements will be made a part of the record, as I said, and we'll start with John Gannon. Welcome, and please proceed.

**STATEMENTS OF JOHN GANNON, ACTING CHAIR, NATIONAL COUNCIL ON DISABILITY, ACCOMPANIED BY EDWARD P. BURKE, CHIEF GOVERNMENTAL LIAISON; JAMES HARDY, PROJECT DIRECTOR, UNIVERSITY OF IOWA, DIVISION OF DEVELOPMENTAL DISABILITIES, ON BEHALF OF STATE PROJECT DIRECTORS; AND JENIFER SIMPSON, POLICY ASSOCIATE, GOVERNMENTAL ACTIVITIES, UNITED CEREBRAL PALSY ASSOCIATIONS, INC., ACCOMPANIED BY JOSHUA CHARTIENTZ, ON BEHALF OF THE CONSORTIUM FOR CITIZENS WITH DISABILITIES**

Mr. GANNON. Thank you, Senator.

My name is John A. Gannon, and I serve as acting chairman of the National Council on Disability. With me this morning is Andrei Batavia, executive director, and Edward Burke, chief of governmental liaison for the National Council.

The National Council is an independent Federal agency led by 15 members appointed by the President and confirmed by the U.S. Senate. The National Council's overall mission is to propose national policy that facilitates independent living, community integration, and employment opportunities for people with disabilities.

Over the course of the past 2 fiscal years, the Council was involved in a major research study on the financing of assistive technology and service for people with disabilities. The result of this research, conducted by a very capable contractor, United Cerebral Palsy Associations, Incorporated, was a comprehensive, multivolume, State of the art report on financing of assistive technology devices and services, entitled, "Study on the Financing of Assistive Technology Devices and Services for Individuals with Disabilities." The Council presented this report to the President and Congress on March 4, 1993.

The report contains 16 recommendations, many of which we are pleased to note are addressed in the current staff draft Senate bill.

The National Council is keenly interested in research on assistive technology. And let me State that the National Council concurs with the vast majority of changes to the Act as detailed in the staff draft we received in June.

In our study, we found that the assistive technology devices and services can play a major role in increasing independence and empowering individuals with disabilities in a cost-effective manner. Consider the following findings.

Almost 75 percent of children were able to remain in a regular classroom, and 45 percent were able to reduce school-related services. Sixty-two percent of working-age persons were able to reduce dependency on their family members, and 58 percent were able to reduce dependency on paid assistance.

Eighty percent of older people were able to reduce their dependence on others, and half were able to avoid entering a nursing home.

With outcomes like this, you can understand why the National Council strongly supports the reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act of 1988.

Mr. Burke will not pinpoint the Council's view regarding this draft bill.

Senator HARKIN. Mr. Burke.

Mr. BURKE. Thank you, Chairman Gannon.

I am honored to be before this subcommittee this morning, a group of individuals who have made truly positive changes in the lives of Americans with disabilities, their families and communities.

I would now like to just briefly summarize the Council's views regarding the bill. We find the proposed changes in the "Findings and Purposes" section and the new definitions both timely and responsive to the stated needs of people with disabilities, as is the focus on systemic change and advocacy that has been included in Title I.

The proposed new section 101(b), "Activities," details many possible activities a State may engage in with funding under the Act. We believe that two sets of activities in particular deserve greater attention—the activities on access to and funding for assistive tech-

nology and in subsection (2), "Advocacy." In our view, these are the two activities that should drive the systems change efforts envisioned in the Act and provide the greatest promise that the real needs of people with disabilities will in fact be addressed by grantees.

It is our view that these two activities should be mandatory and that the other nine activities listed should be optional according to a given State's needs.

Another change we would suggest relates to the proposed section 105(c) regarding administrative mechanisms to change a protection and advocacy provider. While this matter is, of course, a rather complicated one, we would suggest that the subcommittee consider the language currently used in the DD Act in section 142, regarding the redesignation of protection and advocacy services, as a basis for language in this Act.

The National Council welcomes the proposed provisions of section 105(f) regarding follow-up on our recent report to the President and Congress, which Mr. Gannon mentioned earlier. We also support the reservation of funds for technical assistance, as proposed in section 106(b).

We strongly support the proposed feasibility study regarding a national classification system in Title II. And in a similar manner, we support the proposed training and public awareness projects in Part B.

We also support language included in this part to ensure that people with disabilities and individuals who are members of minority groups are full participants in the activities funded under this part. This was highlighted in our recent report, "Meeting the Unique Needs of Minorities with Disabilities," which we submitted to the President and Congress in April.

We are also very supportive of the direct loan projects as described in section 231, but would urge the subcommittee to guarantee the Federal match by changing the word "may" to "shall" at the end of line 2 in the staff draft.

There are two other issues we would like to see addressed in the bill if at all possible. The first of these is a focus on the concept of universal product design. It would be quite beneficial to include a specific focus on this under Part D, "Demonstration and Innovation Projects," by adding a new provision to subsection (b)(2) to allow the Secretary to fund a project for a public-private partnership to identify solutions to the issues surrounding the development of universal product design guidelines, and we have submitted specific language on this in our written testimony.

The second area we would hope to see addressed in the reauthorization is the amendment of other Federal laws to facilitate the financing of assistive technology. The distinguished members of this subcommittee are well aware of the barriers often faced by individuals with disabilities and their families in securing needed supports and services. In our report, we cited several areas in current Federal law that, if amended, would provide significantly increased access to assistive technology. We would therefore respectfully suggest that this subcommittee consider amending, or forwarding for amendment, the statutes listed in our written testimony.

These constitute our major recommendations regarding the reauthorization of this vital legislation. In closing, let me once again thank the subcommittee for seeking our views on this matter and express my admiration for the skill and dedication with which you all have approached the great task of increasing the independence, productivity, and community inclusion of Americans with disabilities.

Mr. GANNON. Senator, we are indeed very appreciative of this opportunity to provide the subcommittee with our recommendations on reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act. We urge you to continue in your efforts to clarify and strengthen the Act so that, in the President's words, we can continue to "shift disability policy in American away from exclusion, toward inclusion; away from dependence, toward independence; away from paternalism, and toward empowerment."

Thank you so much, Senator. We really appreciate and acknowledge your support of people with disabilities, and we thank you for your leadership in the passage of the Americans with Disabilities Act.

[The prepared statement of Mr. Gannon follows:]

#### PREPARED STATEMENT OF JOHN A. GANNON

##### INTRODUCTION

Good morning. My name is John A. Gannon and I serve as Acting Chairperson of the National Council on Disability, headquartered in Washington, DC. With me this morning is Ed Burke, Executive Assistant to the Chairperson and Chief of Governmental Liaison for the National Council. As you know, our purpose here this morning is to present our views on the reauthorization of the Technology-Related Assistance Act of 1988. In order to accomplish this in an efficient manner, we will divide our testimony as follows. First, I will present a brief overview of the Council and its work, with particular reference to efforts in technology related research and policy. Next, Mr. Burke will present our specific recommendations regarding the current draft of the Senate reauthorization bill and provide you with our rationales for these recommendations. Finally, I will make closing remarks and welcome any questions you might have. If this is acceptable to the subcommittee members, we will proceed.

##### OVERVIEW OF THE NATIONAL COUNCIL ON DISABILITY

The National Council on Disability is an independent Federal agency led by 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The National Council was initially established in 1978 as an advisory board within the Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed the National Council into an independent agency. This development was essential to allow the Council to provide independent expert advice to the Congress and the Administration. The statutory mandate of the National Council is very broad and was most recently modified by the Rehabilitation Amendments of 1992. (Please see Appendix A for a listing of the Council's specific statutory responsibilities.)

While many government agencies address issues and programs affecting people with disabilities, the National Council is the only Federal agency charged with analyzing and making recommendations on issues of public policy which affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. The National Council appreciates this distinctive opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by assuring an informed and coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life. This puts us in a unique position to conduct cross-disability research on major policy issues affecting all Americans with disabilities such as assistive technology and services.

Consistent with its ambitious mandate, the Council has played a major role in affirming the rights of people with disabilities, increasing opportunities, and improving service delivery systems impacting on the quality of life experienced by people with disabilities. In fact, the Council prepared the initial drafts of the landmark Americans with Disabilities Act, Public Law 101-336, a law that many members of this subcommittee courageously and vigorously led through the legislative process.

#### THE NATIONAL COUNCIL'S RESEARCH ON ASSISTIVE TECHNOLOGY: AN OVERVIEW

Over the course of the past 2 fiscal years the Council was involved in a major research study on the financing of assistive technology and services for people with disabilities. The result of this research, conducted by a very capable contractor, United Cerebral Palsy Associations, Inc., was a comprehensive, multi-volume, state-of-the-art report on the financing of assistive technology devices and services entitled, *Study on the Financing of Assistive Technology Devices and Services for Individuals with Disabilities*. The Council presented this report to the President and the Congress on March 4, 1993. The report contained 16 recommendations, many of which we are pleased to note are addressed in the current draft Senate bill.

The National Council is keenly interested in research on assistive technology. This is based on our firm conviction that progress toward achieving the goals of the Americans with Disabilities Act—to create equality of opportunity, full participation, independent living, and economic self-sufficiency for and with Americans with disabilities—can be greatly accelerated through a national commitment to three essential policy and programmatic issues: expanding opportunities for full social inclusion, personal assistance services, and assistive technology.

The matter before us this morning is the reauthorization of the Technology-Related Assistance Act of 1988. Let me state that the National Council concurs with the vast majority of changes to the Act as detailed in the staff draft we received on June 22, 1993. We are most gratified to see that many of the recommendations we had made in our report, *Study on the Financing of Assistive Technology Devices and Services for Individuals with Disabilities*, are addressed in this draft, including our recommendations regarding a national classification system, an Annual Report to Congress, coordination of Federal efforts, the establishment of Technology Demonstration and Recycling Centers, and the establishment of advocacy safeguards. We believe that this epitomizes both the letter and spirit of our enabling legislation which charges the National Council with the responsibility to study issues in disability policy and to make recommendations to the President and the Congress for necessary changes in law and public policy.

In our study, we found that assistive technology devices and services can play a major role in increasing independence and empowering individuals with disabilities in a cost-effective manner. Consider, if you will for a moment, the following findings reported by individuals and families who had received assistive technology devices and services:

- Almost 75 percent of children were able to remain in a regular classroom, and 45 percent were able to reduce school-related services.
- Sixty-two percent of working-age persons were able to reduce dependency on their family members, and 58 percent were able to reduce dependence on paid assistance.
- Eighty percent of older persons were able to reduce their dependence on others, and half were able to avoid entering a nursing home.
- Ninety-two percent of employed persons reported that assistive technology helped them to work faster or better, 83 percent indicated that they earned more money, and 67 percent reported that assistive technology has helped them to obtain employment in the first place.

With outcomes like these, you can understand why the National Council strongly supports the reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act of 1988. Mr. Burke will now provide you with a brief summary of the Council's views regarding this draft bill.

#### MAJOR RECOMMENDATIONS ON THE REAUTHORIZATION OF THE ACT

Thank you, Chairman Gannon. I am honored to be before this subcommittee this morning, a group of distinguished individuals who have made such positive and historic contributions to the quality of life experienced by Americans with disabilities, their families, and communities. I would now like to present some of our major comments on the draft reauthorization bill.

The proposed changes in the Findings and Purposes Section and the new Definitions are both timely and responsive to the stated needs of people with disabilities. We are also pleased to see the focus on systemic change and advocacy that has been

included in Title I. The proposed new Section 101 (b) ("Activities") details many possible activities a State may conduct with funding under the Act. While we can support any or all of these activities, we believe that two sets of activities in particular deserve greater emphasis: Subsection (1), "Access to and Funding for Assistive Technology" and Subsection (2), "Advocacy". In our view, these are the two activities that should drive the systems change efforts envisioned in the Act and provide the greatest promise that the real needs of people with disabilities will be addressed by grantees. It is our view that these two activities should be mandatory and that the other nine activities listed should be optional according to a given State's needs.

We believe that the Access and Financing activity should be mandatory as we know of no State where this has been adequately addressed. Furthermore, we believe that without a focus on access and financing, all the other activities will cast State efforts adrift in a sea of process, with no guarantee that the result of this process will actually benefit real people in real communities. We believe that the Advocacy activity should be mandatory as well, as experience dictates that advocacy is one of the most potent forces for consumer-responsive systems change. And while some might assert that this will "encourage lawsuits", we believe that the record of the current Protection and Advocacy Systems in the States belies this assertion, as the data indicate that in the vast majority of situations these Systems help consumers solve problems through informal or administrative means, not through lawsuits.

In fact, we believe that the staff draft speaks to the importance of these activities in proposing later in Section 102 (e) (7) that State applications should include " . . . at a minimum, activities in the areas of access to and funding for assistive technology devices and assistive technology services, advocacy, and interagency coordination . . .". The need for advocacy activities is also addressed in Section 102 (e) (19) in which two draft options are presented for "Protection and Advocacy Services". Of the two alternatives, we would support Alternative #1, as we believe that the use of already existing entities would help to avoid fragmentation, lessen potential public confusion, and prove much more cost effective than creating a new system.

We would, therefore, recommend that the proposed Section 101 (b) ("Activities") be amended to clarify that activities in the areas of "Access to and Funding for Assistive Technology" and "Advocacy" are mandatory activities on the part of States. Once this issue is clarified, States may then choose those activities from the remaining list of nine activities which would assist them in creating or enhancing the process by which they accomplish their work.

Another change we would suggest relates to proposed Section 105 (c) regarding administrative mechanisms to change a protection and advocacy provider. While we concur with the proposed language regarding the role of consumers in informing a Governor of their concerns about a given provider, there may be other valid reasons why a Governor may need to change a provider. These reasons should not include political retaliation or punishment for achieving advocacy objectives. However, it could be the case, for example, that a given provider fails in its stewardship role, the net effect of which is a reduction in or total absence of advocacy services. While this matter is, of course, a complicated one, we would suggest that the subcommittee consider the language currently used in the Developmental Disabilities Assistance and Bill of Rights Act in Section 142 (a)(5) regarding the redesignation of protection and advocacy services as a basis for language in proposed Section 105 (c) of the Act under consideration here this morning.

The National Council welcomes the proposed provisions of Section 105 (f) regarding follow-up on our recent report to the President and the Congress, Study on the Financing of Assistive Technology Devices and Services for Individuals with Disabilities, and for the recognition of its important role in the Interagency Disability Coordinating Council. We also support the reservation of funds for technical assistance as proposed in Section 106(b), although we would note that this activity and the funding reserved for it might be more appropriately placed under Title H.

We strongly support the proposed feasibility study regarding a national classification system for assistive technology in Title II, Part A, and appreciate the inclusion of the National Council as a participant in the design of the proposed study. In a similar manner, we support the proposed Training and Public Awareness Projects in Part B and the language included in this Part to ensure that people with disabilities and individuals who are members of minority groups are full participants in the activities funded under this Part. The need to include individuals who are members of minority groups was highlighted in the National Council's recent report, Meeting the Undue Needs of Minorities with Disabilities: A Report to the President and Congress.

We are also very supportive of the proposed Direct Loan Projects as described in the new Section 231 (b)(3) in Part D—Demonstration and Innovation Projects, particularly the provision that the Secretary “may include a requirement that the Secretary shall provide an amount equal to not more than 90 percent of the amount required for any such project”, and would recommend to the subcommittee that the word “may” in this provision be changed to “shall”. Given the financial situations many States currently face, we would want to make it attractive for States to seek this funding (funding which is, by definition, time limited) in order to provide ready access to assistive technology devices and services for persons with disabilities and their families.

#### OTHER IMPORTANT ISSUES THAT NEED TO BE ADDRESSED

There are two additional areas we would hope to see included in the reauthorization bill. The first of these is a focus on the concept of universal product design. The concept of universal product design is an approach that responds to the needs of individuals with functional limitations in the design stage of commercial products. By attending to the needs of individuals with functional limitations in the design stage, we can avoid costly retrofitting, purchase of additional equipment and devices, or—worse—the waste of human potential through no action at all. This concept has already received attention in Section 508 of the Rehabilitation Act and various other statutes. However, it would, in our view, be quite beneficial to include a specific focus on this concept in the Technology-Related Assistance Act under Part D—Demonstration and Innovation Projects, Section 231, by adding a new provision to Subsection (b)(2) to allow the Secretary to fund a project under a new (E), the purpose of which would be to provide funding for a public-private partnership to identify solutions to the issues surrounding the development of universal product design guidelines in a cost-effective manner. The specific additional language we would recommend is as follows:

Add the following provision to Part D: Section 231 (b)(2)

(E) develop guidelines for the utilization of universal product design features in commercial products that are responsive to the needs of individuals with functional impairments and the general public. Such guidelines should be developed with the full participation of individuals with disabilities, rehabilitation engineers, representatives from private industry, and design experts.

The second area we would hope to see addressed in the reauthorization is the amendment of other Federal laws to facilitate the financing of assistive technology devices and services. The distinguished members of this subcommittee are aware of the barriers often faced by individuals with disabilities and their families in securing needed supports and services for which they are supposed to be eligible or even entitled. In our report, we cited several areas in current Federal law that, if amended, would provide significantly increased access to assistive technology and go a long way toward solving some of the financing problems consumers currently face. We would, therefore, respectfully suggest that this subcommittee consider amending (or, for those statutes not directly under its jurisdiction, forwarding recommended amendments to the appropriate committees and subcommittees), for the following purposes, the statutes listed below:

Amend the State plan requirements in the following statutes to require assurances and a planning process with timelines for expanding funding access to assistive technology:

- Rehabilitation Act: Title VI—Supported Employment
- Rehabilitation Act: Title VI—Independent Living Services
- Individuals with Disabilities Education Act: Part H
- Individuals with Disabilities Education Act: Part B
- Social Security Act: Title XIX—Medicaid
- Maternal and Child Health Block Grant: Title V
- Developmental Disabilities Assistance and Bill of Rights Act of 1990
- Older Americans Act

Amend the individual program planning requirements in the following statutes to provide notice (in accessible formats) to individuals with disabilities and their families of the right to assistive technology devices and services in a timely manner consistent with individual needs:

- Individuals with Disabilities Education Act: Part H
- Individuals with Disabilities Education Act: Part B
- Rehabilitation Act: Title I
- Social Security Act: Title XIX

Amend the Social Security Act to include the complete definition of assistive technology devices and services from the “Definitions” section of the Technology-Related

Assistance for Individuals with Disabilities Act and expand access to assistive technology devices and services—through recognition that the major purpose of assistive technology is to do much more than merely “replace or substitute for a missing or malformed body part” in the following Titles:

- Title II—Social Security Disability Insurance
- Title V—Maternal and Child Health Block Grant
- Title XVI—Supplemental Security Income
- Title XVIII—Medicare
- Title XIX—Medicaid

Amend Section 162 of the Internal Revenue Code to allow taxpayers with disabilities who do not itemize the option of claiming assistive technology expenses as above-the-line adjustments to income.

Amend the Communications Act of 1934 to establish and implement a national policy of available, affordable, and accessible telecommunication services for Americans with disabilities.

These constitute our major recommendations regarding the reauthorization of this vital legislation. In closing, let me once again thank the subcommittee for seeking our views on this matter and express my admiration for the skill and dedication with which you have approached the great task of increasing the independence, productivity, and community integration of Americans with disabilities.

#### CONCLUSION

Thank you, Ed. In conclusion, I too would like to state that the National Council on Disability is very appreciative of this opportunity to provide this subcommittee with our recommendations on the reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act. We urge you to continue in your efforts to clarify and strengthen the Act so that, in the President's words, we can continue to, “shift disability policy in America away from exclusion, toward inclusion; away from dependence, toward independence; away from paternalism, and toward empowerment.”

Thank you. We would now be pleased to answer any questions you might have.

#### APPENDIX A

##### Specific Statutory Responsibilities of the National Council on Disability

The overall purpose of the National Council on Disability is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of their disabilities, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society. The specific duties of the National Council to achieve this purpose are as follows:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by Federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act; and all statutes and regulations pertaining to Federal programs which assist such individuals with disabilities in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the Federal, State, and local levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access for health care, and policies that operate as disincentives for the individuals to seek and retain employment.
- Making recommendations to the President, the Congress, the Secretary of Education, the Director of the National Institute on Disability and Rehabilitation Research, and other officials of Federal agencies, respecting ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing the Congress, on a continuing basis, advice, recommendations, legislative proposals, and any additional information which the Council or the Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.).
- Advising the President, the Congress, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the Director of the Na-



tional Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.

- Providing advice to the Commissioner with respect to the policies of and conduct of the Rehabilitation Services Administration.

- Making recommendations to the Director of the National Institute on Disability and Rehabilitation research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.

- Submitting an Annual Report with appropriate recommendations to the President and Congress with a particular focus on new and emerging issues impacting on the lives of individuals with disabilities.

- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of such Council for legislative and administrative changes to ensure that such recommendations are consistent with the purposes of the Council to promote the full integration, independence, and productivity of individuals with disabilities.

- Preparing and submitting to the President and the Congress a report entitled National Disability Policy: A Progress Report on an annual basis; and

- Preparing and submitting to the Congress and the President a report containing a summary of the activities and accomplishments of the Council on an annual basis.

NATIONAL COUNCIL ON DISABILITY, 800 INDEPENDENCE AVE, SW,  
Washington, DC, June 29, 1993

The Honorable Tom Harkin,  
United States Senate,  
113 Hart Senate Office Building,  
Washington, DC.

DEAR SENATOR HARKIN: Thank you very much for the opportunity to testify at this morning's hearing on the reauthorization of the Technology-Related Assistance Act of 1988. We fully support the reauthorization of this vital legislation and trust that our testimony provided you and the staff of the subcommittee with useful information. As we stated this morning, we believe that strongly focusing the attention of the States on the areas of finance and advocacy and including some discretionary authority for the Secretary of Education to fund projects in the area of universal product design would greatly strengthen the Act.

Per your request, I have enclosed a copy of the "Benefit-Cost Study of the Provision of Assistive Technology Devices and Services" that was a part of the Council's Study on the financing of Assistive Technology Devices and Services for Individuals with Disabilities. While the data presented in this document is based on a relatively small sample (N= 136), we were overwhelmed with the consistently positive relationship between the provision of appropriate assistive technologies and services and the increased independence, productivity, mobility, integration, and earning power of consumers. We are confident that replications of this study would yield similar results, as these findings were echoed in statements made by consumers at the three public hearings we held on the financing of assistive technology last year.

The individuals in our study were asked to complete a written questionnaire and then participate in a telephone interview. They were from four age groups: infants and toddlers, school-age children, working-age individuals, and senior citizens. The questions were structured to gather information about the impact and benefits to the individual of assistive technology in terms of health status, independence, productivity, integration, and prevention of secondary disabilities. Major findings from the study included the following:

1. The majority of infants with disabilities benefited by having fewer health problems because of assistive technology.

2. Forty-four percent of the families were able to use child care or decrease the amount of parental care because of assistive technology.

3. Almost three-quarters of school-age children were able to remain in a regular classroom, and 45 percent were able to reduce their use of school-related services.

4. Sixty-two percent of working-age persons were able to reduce dependence on family members, 58 percent were able to reduce dependence on paid assistance, and 37 percent were able to increase earnings.

5. Among elderly persons, 80 percent were able to reduce dependence on others, half were able to reduce dependence on paid persons, and half were able to avoid entering a nursing home.

6. Ninety-six respondents identified specific types of assistive technology that would make a difference in their lives. The average cost of this equipment was

\$5,645; respondents indicated that they would be willing to pay an average of \$1,421 for this equipment.

7. Among the benefits attributable to assistive technology were time savings in activities of daily living (ADLs) and household chores; time savings in reading, writing, and studying; more time spent on community participation; and monetary savings. Sixty-four percent of those reporting time savings reported reduction in ADL time; 48 percent reported less time reading, writing, studying, or learning; and 43 percent reported less time on household chores. The average time saved in a week was 19.8 hours for ADLs, 16 hours for reading, writing, studying, or learning; and 15 hours for household chores. This time saving allowed persons with disabilities to engage in an average of 15 extra hours of recreation and more than 10 hours of extra time with the family.

8. Sixty-six percent of respondents reported that they were able to visit family and friends an additional 10 visits per month, and everyone reported making new friends and participating more in community activities.

9. Almost one-third of the respondents indicated that their family saved money, averaging \$1,110 in the previous month. At the same time, one-quarter of the respondents indicated that they experienced additional equipment-related expenses, averaging approximately \$287 per month. Nevertheless, almost one-quarter of the respondents reported that their family members could work an average of an additional 25 hours each week, although only 5 percent reported that they earned more money. For those reporting additional earnings, the average was approximately \$249 each week.

10. Of the 42 respondents who reported having paid jobs, 92 percent reported that the assistive technology enabled them to work faster or better, 83 percent indicated that they earned more money, 81 percent reported working more hours, and 67 percent reported that the equipment has enabled them to obtain employment. Fifteen percent indicated that the equipment has enabled them to keep their jobs. Equipment also enabled 38 percent to pursue additional schooling.

11. From a societal point of view, equipment was reported to have enabled 6 out of 36 Social Security Disability Insurance (SSDI) beneficiaries to reduce their SSDI payments an average of \$572 per month, while 5 out of 31 Supplemental Security Insurance (SSI) recipients reported a reduction in 551 payments, averaging \$261 per month, because of the use of assistive technology. Of the 16 persons who reported reductions in public transfer payments, the total was \$5,240 per month or an average of \$327 per person. A smaller number reported a reduction in public expenses for social services as a result of their use of assistive technology.

12. Most importantly, when asked to estimate the impact of equipment on their quality of life on a scale from 1 to 10, respondents reported that without the equipment their quality of life was around 3, while their quality of life jumped to approximately 8.4 points with the equipment.

I do hope you find this information helpful as you finalize the Senate version of the reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act of 1988. As always, please feel free to call on us any time that you believe we may be of assistance to you or your staff; we're here for you!

In closing, let me once again thank you for the opportunity to testify at this morning's hearing and commend you for the tremendous leadership you have exhibited in improving the quality of life experienced by Americans with Disabilities, their families, and communities.

Sincerely,

JOHN A. GANNON  
Acting Chairperson

## Section Seven

Benefit Cost Study of the Provision of Assistive  
Technology Devices and Services

Excerpted from:

National Council on Disability (1993). *Study on the Financing of Assistive  
Technology Devices and Services for Individuals with Disabilities*. Washington,  
DC: Author.

## Survey Sampling Procedure &amp; Methodology

In 1991 the NCD contracted with human service delivery agents in nine different states<sup>7</sup> to conduct a survey of persons with disabilities who were users of assistive devices. The survey objective was to determine the various costs and benefits that respondents from four age groups ascribed to the use of their assistive devices. The age groups consisted of: 1) children under age five; 2) youths aged five through 21; 3) working-aged adults aged 21 through 65; and 4) persons older than 65. (Guardians were asked about any children under age 21 using such assistive technology.) Each interviewer attempted to fill out four surveys for each of the four age groups for a total of 16 surveys per state.<sup>8</sup> Interviews were conducted during the first four months of 1992. The final sample consisted of 136 respondents.

Each state surveyor was instructed to complete a two part phone interview to identify the appropriate target sample. The first part sought to identify a user of assistive devices in one of the given four age groups. The types of equipment used that were most beneficial were then identified. Respondents were subsequently asked to categorize the nature of the benefits for a given age group that are attributable to usage of these devices.

A total of 58 Part 1 telephone surveys were coded into the data base. Several of the households had more than one person with a disability and using assistive devices. The position of the persons with disabilities within the family structure and descriptive statistics about their respective ages are provided in Table 3. The sample frame included nine children under age five, 11 youths aged five through 21, 28 working-aged adults and ten respondents older than age 65.

Table 3: Family Status and Age of Person with Disability

Family Member:	Frequency	% of Responses	Age		
			Average	Minimum	Maximum
Respondent	39	68.42	49.45	26	81
Son	11	19.30	9.18	3	17
Daughter	10	17.54	7.60	2	22
Spouse	8	14.04	49.57	36	84
No Response	79				

## Preliminary Screening Interview Results

This screening interview obtained preliminary information on a person's most useful assistive devices. A total of 40 different classifications of assistive devices were identified. The most popular were mobility, transportation, computer and communications devices. Wheelchairs were mentioned 43 times, vans with lifts, and modified door handles or controls were listed eight times, computers five times and by the 58 respondents.

Depending on the age classifications, many of these respondents benefited from assistive technology in ways which had a significant impact on a major life activity. The various benefits for a given age classification are reported in Tables 2-5 below. While the small sample sizes and selection bias must be noted, the use of assistive devices appears to have generated substantial improvements. Parents of the majority of these infants identified as having a disability concurred that assistive devices had prevented health care problems. The second most frequently mentioned benefit (44%) due to assistive technology was the reduction in parental care or child care. Similarly, adaptive equipment enabled more than 70% of the youth cohort to remain in a mainstream classroom setting. Almost half were able to reduce their usage of school-related ancillary services. A majority of working-aged adults reported reduced dependence on family members and paid assistant. Also note that more than three-eighths of those responding reported increased earnings attributable to their assistive devices. Finally, half of the elderly cohort reported that assistive devices enabled them to avoid entering a nursing home and reduced their dependence on paid assistants. Eight of the ten respondents noted a reduced dependence on others.

Table 2: Benefits of Equipment for Infants (Under Age 3)

Type of Benefit:	Frequency	% of Responses
Use Child Care or Reducing Parental Care	8	44.44
Enter Integrated Child Care or Preschool	7	37.77
Prevent Health Care Problems	3	15.56
Other	4	21.47

The survey benefits of child equipment for infants under age 3. In this response include: play with toys, improved communication, attend blind school, better understanding, better communication, and improved health safety.

Table 3: Benefits of Equipment for School Age Children (Age 3-21)

Type of Benefit:	Frequency	% of Responses
Move from Special to Regular Education	3	27.27
Remain in a Regular Classroom Setting	8	72.73
Reduce Amount of School-Related Services	3	45.45
Other	4	36.36

The survey benefits of child equipment for school age children. In this response include: improved communication and participation, increased independence (2), and improved ability and freedom.

Table 4: Benefits of Equipment for Working-Age Persons (Age 22-64)

Type of Benefit:	Frequency	% of Responses
Reduce or Eliminate SSI Payments	7	24.41
Earn a Salary for First Time	3	10.34
Increase Earnings	15	37.95
Reduce Dependence on Family Members	18	42.07
Reduce Dependence on Paid Assistants	17	38.67
Leave Sheltered Employment	1	5.45
Other	7	21.14

The survey benefits of child equipment for working age persons. In this response include: increased independence (2), greater involvement, continue working, own transportation, become employed, and greater understanding.

Table 5: Benefits of Equipment for Elderly Persons (Over 65 Years)

Type of Benefit:	Frequency	% of Responses
Avoid Entering a Nursing Home	5	50.00
Be Discharged from a Nursing Home	1	10.00
Reduce Dependence on Others	8	80.00
Reduce Dependence on Paid Persons	5	50.00
Other	2	20.00

## Part II Results: Utilization, Costs and Benefits of Assistive Technology

The second part of the questionnaire then sought detailed information about costs of usage, access to, productivity-related benefits and willingness-to-pay for assistive devices. In the first section the interviewers asked respondents to identify all the cost-related aspects of acquiring and maintaining the identified devices. These questions addressed ownership and financing issues as well as out of pocket expenses and any auxiliary costs of using the equipment that may have been incurred. Difficulties in obtaining funding from different sources were also identified. An attempt was also made to identify any additional expenses related to using the equipment for activities that were previously not possible.

### Usage and Ownership of Assistive Devices

The questionnaire categorized nine broad classifications of assistive devices: 1) aids for daily living; 2) environmental access; 3) control and manipulation; 4) mobility; 5) computer access and use; 6) hearing; 7) visual and reading; 8) speech; and 9) recreation. Within these categories the respondents were asked to identify which of 39 different types of assistive devices they had used in the past year. They were then asked if they owned, rented, leased or borrowed this equipment. The results are reported in Table 6 below.

Table 2: Use of Assistive Technology by Type

	Used in Past Year	NUMBER OF RESPONDENTS WHO HAVE			
		Owned	Rented	Leased	Received
Alarm/Warning Call System	4	7	3		
Personal Care Aide	78	72	4	1	
Recreational Equipment	47	34	5		1
Feeding/Food Preparation Aids	14	10			
Adaptive Furniture	32	17	1		1
Transfer Equipment	10	11	1		1
Adapted Clothing	6	7			
Home Modification	34	17	5		
School Modification	10				1
Workplace Modification	6	1			1
Public Accommodation	10				1
Seating & Positioning	77	10	1		7
Prosthetics/Orthotics	29	29			
Functional Electrical Stimulation	3		1	1	1
Personal Robotics	1	1			
Environmental Control	5	6			
Van Modification	31	35			1
Driving & Transportation Aids	17	30		1	
Walking/Standing Aids	79	72	1		5
Manual-Wheeled Mobility	60	47	2		1
Power-Wheeled Mobility	48	48			1
Car/Van Purchase	4	11			
Aids for Visual Impairment	2	1			
Computer Hardware	32	31			6
Computer Software	27	20			6
Computer Input Access Aids	19	16			2
Computer Output Access	6	7			2
Braille Devices	2	2		1	
Assistive Listening Devices	7	3			3
Deafness Aids	6	6			
TDD Equipment	3	2		1	
Braille and Tactile Aids					
Low Vision Aids	10	3			2
Voice/Media Output Aids	4	3			1
Augmentative Comm. Aids	44	10			2
Real Speech & Artificial Speech	2	1			1
Adapted Toys	6	3			2
Adapted Controller	11	6			1
Tasking Books	1				1

Mobility items were the most prevalent with between one-eighth and one-third of respondents using power or manual-wheeled chairs, van modifications, walking/standing aids or driving and transportation aids. Aids for daily living -- including bathroom equipment, personal care aids, adaptive furniture, transfer equipment and eating aids -- were the next most prevalent, ranging from 10 to 31 percent utilization. Computer access was third most used class of devices. The use of computer hardware, software and input access aids had utilization rates ranging between 15 and 25 percent of respondents. The control and manipulation category was the last category with any significant utilization; usage in the prior year of seating and positioning and orthotics each was listed by 15 to 201 of respondents.

In most instances the devices were owned by the respondents. In the case of both personal care aids and home modifications five respondents (out of 28 and 34 who used such devices in the past year) rented their units. Similarly, about 201 of the respondents borrowed either walking aids, and computer hardware and software.

#### Cost of Assistive Devices

A circumspect analysis of the costs of assistive technology should include the full costs of the resources used for assistive devices. These costs should include all costs of provision -- both publicly and privately funded as well as the out-of-pocket expense for the individual and/or their family. The survey requested cost information on the latter charges. These included not only the initial purchase price but any costs for training in the use of the device, customization charges, all maintenance and any other sundry costs incurred. Also included should be the additional costs now incurred related to the ongoing usage of the equipment.

The Appendix Table 1 contains descriptive statistics for each of these costs by individual assistive device. In very few of the 19 types of assistive devices did more than half of the users bear any out-of-pocket expenses. One can also see that some respondents were users but couldn't provide what the out-of-pocket costs were. As can be inferred, some respondents were users of several assistive devices.

An aggregate picture of the various out-of-pocket expenditures for assistive devices by the respondent is presented in Table 7 below. The number of devices column reflects the fact that persons use more than one device. For instance, there were 178 devices for which out-of-pocket expenses were reported. However, there were only 136 persons in the sample, and, as noted above, many of these people incurred no out-of-pocket expenses even though they owned various assistive devices. The cost per respondent column includes all persons in the sample (i.e., the total costs are divided by 136 respondents in each case). The dollar value of all expenditures listed on the survey totalled \$265,952. The average total expenditure for all cost categories was \$1,956 per respondent.

Table 7: Aggregate Costs of Assistive Devices

Cost Category:	Number of Devices	Total Costs	Cost per Device	Cost per Respondent
Out-of-Pocket	178	\$191,358	\$1,075	\$1,407
Training	76	\$4,995	\$58	\$32
Customization	92	\$38,941	\$421	\$286
Maintenance	101	\$14,110	\$137	\$104
Other	46	\$17,124	\$372	\$126

There were also occasions where persons reported additional expenses related to using assistive equipment. Almost one fourth of the respondents indicated they had incurred such expenses for such items as travel expenses, insurance costs and attendant care. These expenses ranged from \$5 to \$1,500 and averaged \$287 per respondent reporting additional costs. When these costs were added across all respondents the average out-of-pocket costs increased to \$2,025 per person.

Senator HARKIN. Mr. Gannon, Mr. Burke, thank you very much for a fine statement, and I will come back for some questions in a second.

We will turn now to Mr. James Hardy on behalf of the Iowa State project director. Mr. Hardy, it is good to see you again.

Mr. HARDY. Mr. Chairman, I deeply appreciate being here and to have the opportunity to comment regarding the reauthorization of what has become known nationally as the "tech bill."

In addition to more than 35 years of professional and administrative experience with services to persons with disabilities, that includes assistive technology services, my oldest son, who has a severe physical disability, is an assistive technology user. Therefore, when the Iowa University Affiliated Program became the lead agency for Iowa's Title I grant, and I became the director of our Iowa Program for Assistive Technology when it was funded in 1990, I certainly could attest to the paucity of assistive technology services that were available and their lack of consumer-responsiveness.

I have coordinated discussions of the directors of the Title I State grants regarding their perceptions of needed changes in the legislation upon its reauthorization, and I thank the staff for their considerations of our recommendations.

We believe the tech bill was visionary for at least the following. One, it was the first legislation that specifically calls for efforts to change services for persons with disabilities to become consumer-responsive. Two, the purposes of the Act call for the State grant programs to work for systemic change in these services. And three, the legislation permits each State to devise the ways to achieve the purposes according to the specific needs of and the political and systems structures that are unique to each State.

However, the originally provided 5 years for the State grants obviously will not be sufficient to accomplish the grants' purposes. Among the reasons are that it takes a very long time to learn the most effective ways to work with consumers, all service providers, and all appropriate State agencies and policymakers.

Also, the current fiscal situation in most States makes it impossible to effect changes in service systems that require commitment of State funds. Most importantly, bringing about consumer-responsiveness in systems that serve persons with disabilities requires a shift of attitudes and procedures that are endemic to these systems. Permanent changes will be effected only through extended advocacy and education programs to instill the needed attitudes and collaborations among consumer constituencies, service providers, and again, policymakers.

The directors believe that the investment in these programs will pay even greater dividends by the provisions in the discussion draft that extend them beyond the initially authorized 5 years. The discussion draft also includes other provisions from the directors' recommendations, such as an increased emphasis on training programs in Title II.

The parts of the draft that clearly delineate these grants as systems change programs define consumer involvement and specify some of the important implications and outcomes I believe will pro-

vide the States with more leverage to bring about the needed systems change.

The directors strongly believe that advocacy activities to assist consumers to gain their rightful access to assistive technology services and assistive technology are requisite for the most rapid and permanent systems change. However, they believe with equal firmness that the manner in which these activities are being carried should continue to be left to the discretion of the States. Therefore, I believe the directors would prefer alternative number 2 in this regard that appears in the discussion draft, since it provides more flexibility than does alternative number 1.

The directors and their staffs, officials of NIDRR, staff of the resident TA project, and numerous others have worked consistently to overcome the problems that have been faced by all of these State programs. There is now mounting evidence that the grants are becoming effective. Consumers becoming advocates for their needs is only one example that will perpetuate the outcomes of these programs. As Casey Hayse just testified, that certainly is the case in Iowa.

I too wish to thank this subcommittee for the broad program of legislation on behalf of persons with disabilities in recent years and, specific to today's proceedings, for making it increasingly possible for them to obtain assistive technology.

Thank you.

[The prepared statement of Mr. Hardy follows:]

PREPARED STATEMENT OF JAMES C. HARDY, PH.D.

Mr. Chairman, it is an honor for me to be here, and I deeply appreciate the opportunity to comment regarding reauthorization of P.L. 100-407, or what has become known nationally as the "Tech Bill." I am Director of the Iowa Program for Assistive Technology, Iowa's State grant program as authorized by Title I of the legislation. In 1991, I was asked to coordinate considerations by the Directors of these state grants for needed changes in this legislation upon its reauthorization. As a group of citizens with specialized knowledge regarding these needs, we have maintained a constant dialogue since that time. Your staff have been exceedingly responsive and helpful in responding to the results of this dialogue and by involving me in the discussions of that have led to the draft being considered in this hearing.

There are additional perspectives, however, upon which I base my comments. As a Professor of Pediatrics and Speech Pathology at the University of Iowa, I have over 30 years of experience in teaching, research, and clinical work with persons who have communication disorders as a result of malformation, disease of, or injury to their brains and nervous systems, many of whom have numerous other severe and complex disabilities. In the early 1960's I was associated with a group of speech-language pathologists at what is now the Iowa University Dated Program (IUAP) who began the first organized clinical program for what is now called augmentative and alternative communication systems. This program was for children with severe neuromotor involvement of their speech producing mechanisms that was most frequently associated with cerebral palsy.

In 1979 I became the Director of the interdisciplinary clinical services of the IUAP in which more than 1,600 children and young adults who have complex disabilities are seen annually. These services include assisting these children, young adults, and their families to obtain needed assistive technology of all types.

In 1981, my eldest son sustained a crushed cervical-five vertebra in a vehicular accident, and I was thrust into the role of a parent seeking the needed assistive technology for a young man who has no function of his legs and very limited function of his arms and hands. Consequently, I became thoroughly acquainted with the fact that funding streams and service systems for persons with disabilities frequently are not consumer-responsive.

Consequently, Senator Harkin, I welcomed with great enthusiasm your visit to the IUAP in 1986 as you were working to become acquainted personally with assistive technology needs of persons with disabilities and to view the types of tech-



nology that are used by the children and young adults we serve. When the IUAP was designated as Iowa's lead agency for its Title I state grant, I eagerly accepted the assignments to coordinate drafting Iowa's application and to direct its program when the application was funded in 1990.

From the initial work to determine the assistive technology needs of Iowans that formed the basis of Iowa's application to this day, the activities with the Iowa Program for Assistive Technology have convinced me that the "Tech Bill" was a visionary piece of legislation, and, based upon information available at that time, it was remarkably well drafted to assist in meeting the unbelievably extensive needs for assistive technology by persons with all types of disabilities of all ages. The Directors of the state programs share these perceptions of the outstanding characteristics of the law.

Although earlier legislation required some services to be organized in ways that enhance the rights of persons with disabilities in receiving services (e.g., P.L. 94-142, The Education of All Handicapped Children Act), the Tech Bill was the first that calls for enhancing services for persons with disabilities in a way that they, the services, are consumer-responsive.

The term "systems change" was not used in the Act of 1988. Nevertheless, the purposes that are articulated therein clearly call for the State grant programs to work for a comprehensive systemic change in all of the funding and service systems for persons with disabilities.

Also, ways in which each state can proceed to accomplish the purposes of the legislation is discretionary. Each state can devise ways to achieve the purposes according to the specific needs within the state and the political and systems structure that are unique to that state.

These, and other, farsighted characteristics of the legislation, however, have created an enormous task that requires, I believe, far more time to accomplish than anyone anticipated. Speaking from the Iowa experience, it has taken an extraordinary expenditure of time and effort to learn the most optimally effective ways to work with consumers, service providers, and policy makers.

As is well known, the needs for enhanced, comprehensive, consumer responsive assistive technology services transcend all service systems for persons with all types of disabilities from infants and toddlers to persons who are elderly. Those services that must be impacted reside with education—both special and regular education—programs, social service programs, public health programs, and private sector service programs. In addition, numerous private sector entities must also be impacted. For example, changing the practices of vendors of assistive technology devices has surfaced as a requisite need in Iowa. Groups of non-traditional service providers have been identified that were not anticipated. An example is that consideration must be given to involving pharmacists in awareness and advocacy initiatives in reaching persons who are elderly, who have disabilities, and who need access to assistive technology services.

Consequently, the Directors of the state grants submit that

1. The tasks required are much too broad and extensive to be completed in the 5 years that are called for by the 3-year development and 2-year extension grants provided in the original legislation.

In addition,

2. As the need for enhanced assistive technology services has become more apparent and the opportunities/requirements to provide these services have increased through other federal legislation (e.g., P.L. 101-336, The Americans With Disabilities Act; P.L. 101-476; The Individuals With Education Act; P.L. 102-569, The Rehabilitation Act Amendments), the resources of the state grants have been taxed far more than was anticipated. This broad program of new legislation has, most desirably, mandated involvement of public and private sector entities in providing assistive technology services that previously had little vested interest in doing so. As these entities are moving rapidly to comply with the new legislation, they are calling increasingly on the state grant programs to assist them.

3. The current fiscal situation of most states is making it impossible to effect changes in service systems where these changes require commitment of state funds.

4. Where resistance to systems change is being encountered, the limited time of the grants permits agencies and service systems to disregard efforts to accomplish change since there is recognition that these efforts will no longer be present after 5 years.

Systems change is a complex process which will result in permanent changes only through an extended period of vigilance, advocacy, and education. It would be most unfortunate if the systems change initiatives of these grants were abandoned before it is certain they will be continued through implementation by state and national programs.

5. Most importantly, all of the above mentioned systems that serve persons with disabilities, generally, are not consumer-responsive. It is unrealistic to expect that these grant programs can bring about a consumer-responsive system of services within 5 years, since to do so requires a shift of attitudes and procedures that are endemic to services for persons with disabilities. More time will be required to ensure that the attitudes and collaborations among and between disability constituencies, service providers, and public agencies will become permanently ingrained in our society.

Therefore, it is the primary recommendation of the Directors of the Title I grant programs that the grants be extended beyond the 5 years provided in the original legislation. We are exceedingly pleased that the Senate staff discussion draft includes a provision for extending the grants for an additional 3 years.

Also, the Directors recognized that restrictions are being placed upon some of their operations due to regulations of the agencies in which they work. Therefore, they have asked that the reauthorization specify assurances that these restrictions will be waived. They also requested that the arrangement for operationalizing the activities of the national technical assistance program be made more flexible. Finally, the Directors believe that projects for training of consumers and service providers be given a higher priority in Title II.

We deeply appreciate the staffs' positive response to these recommendations, and the provisions in the discussion draft that make these changes will result in more rapid realization of the purposes of the legislation. In addition, there are numerous changes that the Directors have discussed as being desirable that are included in the draft. Clearly articulating that these grants are systems change programs and specifying some of the important implications are examples.

The Directors strongly believe that advocacy activities to assist consumers to gain their rightful access to assistive technology and assistive technology services are requisite for the most rapid and effective systems change. However, they believe with equal firmness that the manner in which these activities are to continue to be carried out should be left to the discretion of the states. Therefore, if it is believed necessary to require an assurance that these activities be a part of a state's program, I believe that the Directors would prefer Alternative #2 of the alternate provisions regarding protection and advocacy services that appear in Section 102, (e), (19) of the discussion draft.

The required assurance for cooperation with other systemic change projects [Section 102, (e), (20)] may be problematic. While such cooperation is unquestionably desirable, the political situation in some states may make obtaining that assurance impossible. Also, the involving a state's "Insurance Department" directly in these grant programs [Section 101, (e), (2), and Section 104, (4)] may result in problems. Because of the regulatory authority of these offices, insurance companies are likely to be reluctant to enter into systems change activities when these offices are involved.

There is mounting evidence that these state grants are being effective in bringing about comprehensive consumer-responsive systems of assistive technology services. One of the more exciting evolutions that results from the advocacy activities of the state grant programs is the surge of consumer interest and confidence that these programs are (1) working on their behalf and (2) that they are initiatives that will have a very favorable long-range impact upon their lives. Consumers are learning how to advocate to meet their needs, which will perpetuate the outcome of the programs. That certainly is the case in Iowa.

It must be recognized that the expectations for these programs by consumers, their advocacy groups, and all of us working to achieve the grants' purposes for these programs were unrealistically high. Fortunately, with the flexibility provided to the states and the approaches taken by the state programs, these expectations are being tempered by the realization that (1) consumers must acquire considerably more information, (2) a completely different orientation on the part of policy makers and service providers must be gained, and (3) there must be significant reallocations of resources to achieve the grants' purposes.

Iowa's program has faced numerous difficulties, as have all of the other state programs, and the officials of the National Institute of Disabilities and Rehabilitation Research and the RESNA Technical Assistance Project have certainly worked to help resolve these difficulties. It must be realized that there are numerous exceedingly successful initiatives that have been implemented across the nation. Providing thousands of consumers with information as to how to access existing funding streams so that they may obtain assistive technology services and assistive technology is only one example. In view of the growing accomplishments of these programs, it is unfortunate that there are perceptions that selected instances of specific difficulties are generally applicable to all of the programs.

There are no hard data to demonstrate the best way to bring about the comprehensive and sweeping systems change called for. We are all learning in this process of bringing about statewide, consumer-responsive systems of assistive technology services. The provisions in the Senate staff discussion draft that call for changes in the purposes of the legislation and increased accountability is a result of this learning. These changes will provide more leverage for the state programs to bring about change and to demonstrate that change.

Finally, I speak for not only the Directors of the state programs, but also their staffs, and, I believe, the persons with disabilities throughout our nation in thanking this subcommittee for its foresight in making it increasingly possible for persons with disabilities to obtain needed assistive technology services.

Senator HARKIN. Mr. Hardy, thank you very much for your testimony, and we will come back to you for some questions, but first, we will turn to Jenifer Simpson, with United Cerebral Palsy Associations.

Ms. SIMPSON. Mr. Chairman, members of the committee, I am Jenifer Simpson, and I am here today on behalf of the Consortium for Citizens with Disabilities to talk about the reauthorization of the Tech Act.

As you know, CCD is a working national coalition of more than 100 groups representing individuals with disabilities, providers and professionals, as well as many consumers. We know that assistive technology is critical to the lives of every individual with a disability in America, including for my son, 8-year-old Joshua, who is in the back of the room, misbehaving, but he is a big user of assistive technology and, as you can tell, he couldn't get here if he didn't have a wheelchair.

CCD believes that the mission of the State Tech Act programs is to assist in fulfilling the promise of the Americans with Disabilities Act. Assistive technology must become better understood as a means to achieve reasonable accommodation as a part of the civil rights protections for all Americans with disabilities afforded by the ADA.

CCD's discussion has focused on systems change—what it should be and what the Tech Act programs should be doing in order to give the taxpayers the best value for their money. Our overriding recommendation is to mandate that each State program fund three specific activities to promote systems change, advocacy, and consumer-responsive. We recommend targeting specific activities as critical to ensuring systems change, while at the same time maintaining flexibility for the State programs.

We consider access to funding as paramount. We think that the special ed programs, vocational rehabilitation and Medicaid assistance programs should be the focus of systems change activities by these State Tech Act programs. These programs are federally-funded; they cut across every age, and potentially, every child and youth and adult with a disability could get the assistive technology they need if the individual plans in those programs were looked at more closely, and the assistive technology they needed were given them when they ask for it.

For instance, my son has had in his IAP for the last 4 years the need for an augmentative communication device so that he could reach literacy and communication goals. So far, the system has not responded and given him what he needs. I am the driver of the system. I would like more consumer-responsiveness within my local school district in order to make sure he gets what he needs.

In terms of systems change, we appreciate greatly what we see in the draft bill in terms of the definition and the other emphases. We see systems change as actions that will result in increased access to funding that will continue on a permanent basis.

For instance, if we did have a Tech Act program in the District of Columbia, maybe Joshua would have his communication device, and maybe he would be the one testifying here today. This would be a big change, I think.

Most central to CCD's recommendations is an advocacy component. We recommend a very narrow definition of this activity, and by this, we mean the potential for legal representation. We recommend that it also be funded by a 10 percent set-aside of funds. We believe it is necessary that this activity be contracted also the States' protection and advocacy agencies, as authorized under the Developmental Disabilities Act.

We would not feel so strongly about this advocacy set-aside if it were easy for individuals with disabilities to get what they need. Direct service agencies often have a conflict of interest with systems change activities. An entity such as a P and A in the outside role, which can support the lead State agency, also offers protection to individuals to get what they need.

To establish this within the Tech Act opens the door for every individual to get what they need.

Consumer responsiveness is also critical for individuals with disabilities, and we appreciate the new definitions and other mechanisms in the Senate draft. Our idea about true consumer responsiveness goes beyond just getting devices. It means sensitivity to individuals. If there were true consumer responsiveness, for instance, in New Mexico, I would not have gotten a phone call that I got recently, from a dad of a 13-year-old with multiple disabilities. The family is Navajo, and they had programmed both English and Navajo into their device. When they moved to a new school district, the old school district would not let the family take the device with them, saying it was theirs. So the dad called me, very frustrated, saying, "What do we do?" He said that the new school district would give a device, but it had a male voice and only English in it. My simple solution was to just switch devices and make an exchange.

This is the kind of suggestion that I think Tech Act programs could do. These are no-cost solutions in terms of policies and practices that can be done at the very local level.

Additionally, CCD understand outreach and training are essential for expanding capacity of States, and these activities must involve the specific constituencies that they are intended to reach. For instance, rural residents, if they get a device in a city by a city provider, they might get home and find the device doesn't work in the trailer because the device is just too big. Inner city areas often lack the infrastructure for even minimal follow-up, sometimes not even the ability to take public transportation. So we understand consumer responsiveness as the State Tech Act programs proactively going to those communities, the inner city or rural areas.

Other highlights that CCD supports in the Senate draft are the provisions for accountability, the onsite visits by NIDRR, to which

the public has been invited, documentation of activities by the Tech Act programs, particularly with regard to what they have been doing with the voc rehab folks, the special education folks, in Parts B and H programs, and Medicaid. We are also very interested in seeing that the assistive technology is considered in the IAPs, the IWRPs, the IFSPs, and other individualized plans that are mandated through these acts.

Also, a mechanism for redesignation of the lead agency is a small but significant amendment in the reauthorization that gives teeth to congressional intent. We also think national technical assistance is very critical. The primary technical assistance recipients right now are the State Tech Act programs and not individuals with disabilities directly.

CCD supports greatly the draft bill provision to address a new critical area of national technical assistance that focuses on the needs of individuals with disabilities and their family members or representatives. It is too much to expect individuals to understand the appeal processes within special ed, voc rehab and Medicaid. This requires expert technical assistance, and this could be offered at a national level.

There is much to be done. There is a paucity of expertise amongst advocates, attorneys, persons with disabilities and professionals across disciplines. I even had to go up to Baltimore to get an expert on assistive communication to get my son properly evaluated, and I live right here in Washington. Training is paramount.

Too often, individuals with disabilities are denied what they need. A communication device may be denied because it is a "convenience"; a wheelchair is denied because it is a "luxury." It almost seems that it is easier to get a handgun than it is to sometimes get some of the things I need for Joshua.

The CCD Task Force on Technology commends and supports greatly much of the work that has gone into the draft. If you could incorporate some of our points made, we think this would strengthen the draft.

I thank the committee for involving and inviting the CCD to participate in the reauthorization process, and I'd be happy to answer any questions.

[The prepared statement of Ms. Simpson follows:]

#### PREPARED STATEMENT OF JENIFER SIMPSON

Mr. Chairman, Members of the Committee, I am Jenifer Simpson and I am here today on behalf of the Consortium For Citizens With Disabilities (CCD) to talk about the reauthorization of P.L. 100-407, the "Technology-Related Assistance For Individuals With Disabilities Act of 1988" [29 USC 2201], referred to as "The Tech Act." CCD is a working coalition of over one hundred consumer, parent, service provider, and professional organizations that advocates on behalf of people with disabilities and their families. The work of the Consortium is conducted by Task Forces in various policy areas such as health care, technology, telecommunications, education, employment, housing, civil rights, taxes, and budget and appropriations. CCD commends the Subcommittee for its leadership in the area of assistive technology and for its strong support of this program over the past 5 years.

The work of the Technology Task Force has, for the past 5 months, been focused on this reauthorization. We have met more than 15 times, read mountains of material about what has been happening in state tech act programs over the past 5 years and have discussed a wide range of issues among ourselves and with other interested parties. These discussions have reflected many varied points of view. What follows are CCD's recommendations for the reauthorization of this legislation resulting from this intensive and exhausting process.

Assistive technology is critical to the lives of every individual with a disability in America, including for my eight year old son, Joshua, sitting next to me today, who has cerebral palsy, and uses a lot of assistive technology. I am testifying today therefore both on behalf of the Consortium for Citizens with Disabilities (CCD) in my role as co-Chairperson of the Task Force on Technology and as a very interested parent.

CCD believes that the mission of the state tech act programs is to assist in fulfilling the promise of ADA--that assistive technology must become better understood as a means to achieve reasonable accommodation as part of the civil rights protections for Americans with disabilities afforded by the ADA. This is what technology-related assistance must be after passage of the ADA. The potential power of the Tech Act far exceeds the current limited federal funding level of 34 million dollars. The reach and impact of Tech Act activities extends across environments, age, race, social class, gender, and abilities. CCD has taken a hard look at what is the best use of the taxpayers' dollars since this amount is clearly insufficient to provide direct service to individuals with disabilities. Therefore our focus has been on systems change, what it should be and what the tech act programs should be doing in order to give the taxpayers the best value for their money. CCD's recommendations focus on Title I.

#### CCD RECOMMENDATIONS FOR SYSTEMS CHANGE

CCD's overriding recommendation for Title I of the Act is to **MANDATE THAT EACH STATE PROGRAM FUND ACTIVITIES SPECIFICALLY ON SYSTEMS CHANGE, ADVOCACY, AND CONSUMER RESPONSIVENESS.**

This means the reauthorized legislation must define these three terms, systems change, advocacy services and consumer responsiveness in addition to requiring that the state tech act programs carry out such activities which CCD sees as essential activities of the programs. CCD is pleased to note that the Senate draft has addressed this with the addition of definitions in the draft bill. CCD further believes it is critical that the statute set priorities that direct and guide the state tech act programs in what they must do and what they can do as optional activities. Specifically, although CCD supports the Senate draft which incorporates the previously authorized "Functions" into "Authorized Activities", CCD does not believe a menu of 12 different authorized activities that a state can select from will effectively accomplish systems change, advocacy and consumer responsiveness. We recommend targeting specific activities as critical to ensuring systems change while maintaining flexibility. Our short list includes:

1. **ACCESS TO FUNDING.** CCD has identified three federal funding streams as critical to securing assistive technology for individuals with disabilities and is pleased that this new emphasis is included in the Senate draft bill. CCD recommends that state tech act programs must focus their systems change initiatives within the special education, vocational rehabilitation and state medical assistance programs. These three programs reach almost every child, every youth, and every adult with a disability who might need assistive technology. Within these programs Congress has already established that the need for assistive technology devices and services must be ascertained and provided when needed by the individual with the disability.

For example, Joshua's Individualized Education Plan specifies that he needs an Augmentative Communication Device in order to reach literacy and communication goals and to be able to talk to his pals and teacher at school. This piece of assistive technology has been written into his IEP for the past 4 years. So far it has NOT been funded by the school system or by another public agency. As the parent, I am the sole driver of the system as I attempt to fulfill this IEP requirement and in fact, I have gone outside the school system trying to access this item.

2. **SYSTEMS CHANGE.** CCD appreciates seeing both a definition and a new emphasis on this in the Senate draft, especially in the new Assurances in the Applications section. We see systems change as the modification, revision, correction, adjustment or transformation of existing state or local policies, practices, procedures or capacity to provide assistive technology devices and services to individuals with disabilities and their families, so that the result is greater capacity or enhancement of funding and or service provision of assistive technology devices and services to individuals with disabilities and their families, with the change continuing on a permanent basis.

For example if we had a tech act program in the District of Columbia, where Joshua and I live, and if they were to carry out systems change activities, it is possible that Joshua would have had his Augmentative Communication Device today and he

would be the one testifying. Unfortunately, though not silent, he is in essence, silenced because there is no systemic initiative to ensure that this need is being met.

3. **ADVOCACY.** Critical within CCD's recommendations is to require advocacy services be provided by the tech act programs. CCD differs in this respect from how we understand the Senate draft bill to read. Not only are we recommending a very narrow definition of this activity, i.e., legal representation, but also we recommend that it be funded by a 10 percent set-aside of funds from each state's program. We believe it is necessary that this activity must be contracted to the state's Protection and Advocacy Agencies (P&A's) authorized in the Developmental Disabilities Act. However, as in the Senate draft, CCD does support that as part of the technology-related assistance undertaken by state tech act programs, they must also see themselves as advocates on behalf of individuals with disabilities in securing assistive technology.

Advocacy is critical to securing assistive technology services and devices. CCD would not feel so strongly on this issue if it were easy for individuals with disabilities to secure the items and services they need. Direct service agencies often have a conflict of interest with systems change activities necessary to respond to the assistive technology needs of individuals with disabilities. Additionally, many state programs need encouragement in their efforts to implement systems change. The existence of an entity in an "outsider" role, such as the P&A would have, supports the efforts of the lead state agency as well as offering protection and advocacy services on an individual basis. The P & A is the only federally funded agency in existence in every state with a mandate, established by Congress already, to protect and advocate for persons with disabilities. To establish the P & A within the Tech Act opens the door for every individual with a disability to potentially be represented with regard to securing the assistive technology devices and services they need.

Let me elaborate with another example: I believe that the only leverage I have had in getting a school bus with a lift is that I might file an appeal. To get the school bus to come to the house on time every day with a lift on the school bus that worked, I had to utilize the due process appeal procedure within IDEA. The school authority had been dispatching a bus with either a broken lift or a bus that broke down, if it came to the house at all, and I had been helping the driver lift Joshua in his wheelchair through the back door of the bus. I had previously hired a lawyer in order to get Joshua's Free Appropriate Public Education. I believe that because the school system knew I might hire a lawyer again, they agreed to sending a bus with an operational lift at the initial meeting instead of contesting and going through the full appeal process again.

Also, CCD is very aware of parents or individuals with disabilities who have less sophistication in knowing how to negotiate the bureaucracy than someone like me who is educated, aware of my rights and has some resources to challenge the system. Laws are not self-enforcing and there are many families and individuals with disabilities who need someone to advocate for them. There are thousands who are told each day that "it can be funded" or "I can't put that into the plan" or "it costs too much" and they go away believing that the authority figure must be right and that they do not deserve the assistive technology item or service.

4. **CONSUMER-RESPONSIVENESS.** CCD expects considerably more consumer involvement, choice and control in the implementation of the statewide system of technology-related assistance and we appreciate greatly the two new definitions of "comprehensive" and "consumer responsive" in the Senate draft. CCD urges that the state programs identify project initiatives to increase consumer participation across age and across disability. Furthermore, states must increase consumer participation, choice and control in the selection and procurement of assistive technology as they work to make the system do this, as they do not provide the services and devices themselves. And they must increase the ability and ease of consumers in identifying their assistive technology needs and in acquiring, and keeping, their assistive technology. Additionally they must increase access by individuals with disabilities to information on assistive technology options, based on the individual's need.

If there were true consumer responsiveness, for instance, I would not have received a phone call from New Mexico that I got recently from a father of a 13-year-old girl with multiple disabilities. The family is Navaho and they had programmed both English and Navaho into her communication device, which is both a very time-consuming but very important activity for this child and her family. When they moved to another school district, within the same state, the local school authority refused to let the girl take the programmed device with her to the new school district. Cultural sensitivity is a critical component of consumer-responsiveness, as much as finding solutions to artificial barriers such as school property rights which get in the way of free expression. My suggested solution to the problem, by the way,

was that the new school district exchange the comparable device they were providing with the one from the 'old' school district.

**5. OUTREACH AND TRAINING INITIATIVES.** There is a critical shortage of quality training programs and trained professionals who are knowledgeable in providing AT services and devices to individuals with disabilities and their families. CCD understands that outreach and training are essential activities for expanding the capacity of the states to provide technology-related assistance. These activities must involve the specific constituencies they are intended to reach in the planning and development and implementation of training and outreach. Representatives from traditionally underserved populations provide a perspective that is invaluable. Such perspectives increase the likelihood that these activities will lead to meaningful systems change.

For example, it is not uncommon for a rural resident with a disability to receive a device through a city-based provider and return home to find that it does not work in the rural environment. Some powered wheelchairs, for instance, can't be maneuvered in a trailer or in older, two-story farmhouses. Issues such as uneven terrain or durability of the device must be considered as well. Additionally, both rural and inner city areas lack the infrastructure for providing even minimal follow-up, technical assistance or maintenance. Service providers based in urban centers often do not understand how to deem income of rural families—particularly those involved in agricultural production—and may count as resources, for means testing purposes, items which would exclude eligibility, such as the value of tools and implements. These communities often lack means of public transportation to get to the clinic or hospital or other setting to try out a device or even to know about a device or service unless the state tech act program has targeted such a community and pro-actively gone to the community.

**CCD ALSO FEELS THAT IN ADDITION TO A SYSTEMS CHANGE MANDATE, ACCOUNTABILITY, NATIONAL TECHNICAL ASSISTANCE AND ALTERNATIVE FINANCE MECHANISMS ARE CRITICAL COMPONENTS TO BE EMPHASIZED IN THE REAUTHORIZATION.**

**ACCOUNTABILITY.** CCD feels strongly that critical to the reauthorization is greater accountability at the state and federal levels and supports wholeheartedly the new provisions for designation of the lead agency, the limitation on indirect costs, and the standards developed in the Senate draft bill. Additionally, CCD supports the new annual Progress Report requirements, including conducting of on-site visits to which the public has been invited. CCD greatly supports any provisions that reflect systems change activities being documented by the tech act programs with regard to their activities in Vocational Rehabilitation, the Special Education (especially Parts B and H) and Medicaid Assistance programs. CCD wants assurances that assistive technology is considered in development of the IEP, IWRP, IFSP, and other individualized plans, in addition to documentation of barriers in these funding streams. CCD wants to see documentation of evidence that the Title I projects have increased responsiveness of these systems to fund assistive technology.

Additionally, CCD feels strongly that the state programs must develop a mechanism for determining consumer satisfaction and documentation of results on an annual basis. CCD wants to see documentation of systems change through (i) the identification of policies, laws, regulations, practices, and other activities that (a) have changed to facilitate the acquisition of assistive technology; (b) need to be changed in the next grant period; and (ii) identification of policies, laws, regulations, practices, and other activities that the Title I project has attempted to change during the grant period, including barriers to achieving such changes.

It is imperative the Secretary develop a set of minimum requirements that guide and assist states to assess the impact and outcomes of required and authorized activities. These minimum requirements—subject to public comment—will also assist individuals with disabilities, their parents, and other interested parties in the states, to evaluate the level of progress their state is making in building the capacity and responsiveness of the system to meet the needs of current and future technology users with disabilities. CCD supports the new provisions in the Senate draft so that Congress and other interested parties will receive more information about federal and state activities and initiatives that improve access of Americans with disabilities to assistive technology.

CCD member groups on the Task Force on Technology reported great frustration with ascertaining the outcomes of activities conducted by the state programs. While we were able to review some of the NIDRR-funded studies authorized initially, such as the NCD report, and the RTI report when we finally received it, we feel that institutionalization of reporting requirements is paramount to monitoring the tech act programs to ensure they stay on track and fulfill their mission. Annual reporting



requirements that are made public and a mechanism for re-designation of the lead agency are small but significant amendments in the reauthorization that will give teeth to Congressional intention.

**NATIONAL TECHNICAL ASSISTANCE.** Current law requires one percent of funds appropriated or \$500,000, whichever is greater, for the purpose of providing to the states information and technical assistance. By the end of this fiscal year, it is expected that all 50 states will be receiving Title I dollars. The demands from states for assistance continue to expand and their needs have become more diverse covering a range of issues including effective approaches to planning and evaluation, outreach, and information and referral, facilitating service delivery capacity building, and assistance in development of training, public awareness and data collection materials.

The current national technical assistance effort does not serve or respond to individuals with disabilities directly. The state lead agency is the primary recipient of such national technical assistance services. CCD commends greatly the effort in the Senate draft bill to address a new critical area of national technical assistance. In particular, the needs of individuals with disabilities, and their family members or representatives, for information and technical assistance on funding access would be greatly enhanced by an additional national technical assistance project staffed by experts on assistive technology systems change, public funding policies, and advocacy services. The Senate draft specifies the activities of such a project to include identifying, collecting, analyzing, and disseminating on a national basis funding decisions made as a result of policies, practices, and procedures, or through administrative hearings or legal action, providing technical assistance on advocacy services and systems change activities, and promoting state-federal solutions to identified funding issues.

The Senate draft bill's provisions, if enacted, would complement the work of the states, lead to more consistent funding decision-making at a local and state level, and would provide a badly needed new resource to be responsive to individuals with disabilities and their families. The activities of such a project should also stimulate greater federal agency oversight and monitoring.

CCD urges increasing the authorization for national information and technical assistance to a level of two million dollars with a minimum of \$750,000 reserved for the technical assistance project focused on state lead agency support and an equal dollar amount reserved for the national information and technical assistance project focused on the needs of individuals with disabilities and their family members or representatives.

**ALTERNATIVE FINANCING MECHANISMS.** CCD has made several recommendations to address the current service provision gap through set up of alternate funding mechanisms to ensure that individuals with disabilities get the assistive technology they need. Organizations involved with individuals with disabilities and their families know that demand for assistive technology services and devices is very high and the institutional barriers that provide access to funds are falling very slowly, and the pressure is acute at the state level to keep budgets from expanding. In the interim, until the state tech act programs have broken through the policy and practice barriers, advocates believe that establishing a Low-Interest Income Contingent Loan Program and a program of Recycling Centers for Assistive Technology Devices would enable individuals with disabilities to quickly have their needs met. Some of the existing programs already do varieties of these activities. In the Reauthorization, these activities should have their own funding stream.

#### CONCLUSION

The passage of the Tech Act was a response by Congress to the widespread lack of collaboration and cooperation between and within various funding agencies. Despite 5 years of Tech Act activities, awareness, understanding, and access to assistive technology devices and services are still too often a result of where you live, your economic class, and your racial heritage. There is so much to be done: still a paucity of expertise among advocates, attorneys, persons with disabilities, family members, and professionals across disciplines who can effectively weave their way through the complex web of federal regulations regarding eligibility and technology funding. There are very different appeals processes through Medicaid, Special Education and Vocational Rehabilitation. The individual with a disability, and his or her family, cannot be expected to negotiate and struggle with the system every time there is a denial or non-response to what is a basic need.

Access to assistive technology has been established as a part of a free appropriate public education for students with disabilities. Is it a right exercised yet for an inner city child in Chicago, Illinois, Minneapolis, Minnesota or a child in the mountains

of Vermont? Work incentive provisions through the Social Security Act remain underutilized as a finance option for assistive technology. In over half the states a PASS (a Plan For Achieving Self Support) has never been developed to access assistive technology. Each month individuals with significant speech disabilities and other multiple challenging disabilities are denied eligibility for rehabilitation services unaware of their right to an assessment of their rehabilitation needs to incorporate assistive technology. In over one third of the states, individuals with significant speech disabilities are denied communication devices on the basis that such devices are a convenience.\* In over half the states, medical and Medicaid policy interpretations will deny an individual freedom of movement and access by determining that a powered mobility system or wheelchair is a luxury item.

During the next few years, the Tech Act offers an opportunity to turn individual funding decisions to precedent setting policy change. As the RTI study suggests, the future of the Tech Projects lies in the success of the states in achieving lasting systems change. Assistive technology as a necessity rather than a convenience, as a critical means to enjoyment of full citizenship, will require a commitment to activism and a renewed sense of urgency. The changes CCD proposes will direct and focus resources to allow us all to work together on a more accessible America. If the state tech act programs undertake the efforts in the direction CCD is recommending, they will be reinventing government and they will play a critical part in restoring the faith of people with disabilities in government as an instrument for change.

The CCD Task Force on Technology commends and supports greatly much of the work that has gone into the Senate draft bill. CCD feels that our recommendations above will further strengthen this Senate draft if incorporated.

Thank the Committee for involving and inviting the Consortium For Citizens With Disabilities to participate in the reauthorization process, essential to true democracy, and I will be happy to answer any questions.

Senator HARKIN. Thank you very much, Jenifer, for being here and for your testimony.

Again, I want to thank the panel for working with us and for meeting with all the interested parties to work out the details in our discussion draft. We continue to build on the success of the ADA by bringing in people and bringing in all interested parties and trying to work together on this. And again, we have one issue in particular that is outstanding. While all of the panel members have supported the concept of supporting individual advocacy, there are differences concerning what the structure of this provision should be, and you have heard that this morning.

So I hope that we can call on each of you to continue to work together so we can reach a consensus on how this advocacy is going to be structured.

We have had 5 years. Mr. Gannon or Mr. Burke, where do you see us 3 years from now in terms of the availability of and access to assistive technology? What would you like to see 3 years from now?

Mr. BURKE. Well, Senator, I think it depends somewhat on the degree to which the Act does become consumer-responsive. And as well I think it depends on the degree to which States are encouraged, maybe mandated, to focus on finance, because the situation out there now that we hear time and again and we heard time and again in our study, is that the good news is there are over 20 potential funding sources for assistive technology. That is also the bad news from the consumer's point of view, because it is very easy for people to get shuffled from one place to another.

That is why we are very supportive of making the focus on finance the true focus of the Act, because I think it would bring things together at this point and really give the States a central focus, as well as the advocacy piece.

So if those pieces are in there, I think the beauty of that is that we will have at the end of 3 years 50 efforts to look at so we can study what the universal barriers have been, what universal, from the Federal level, changes need to be made.

So I think with a consumer-responsive system as well as a focus on finance and advocacy, we'll be a lot further along than we are now.

Senator HARKIN. In your prepared statement, Mr. Gannon, you had some examples or statistics on the financing and the impact it had on individual lives. What I would like to know—is can you expand on those statistics with some specific examples? For example, you said 62 percent of working-age persons were able to reduce dependency on their family members; 58 percent were able to reduce dependence on paid assistance; 83 percent indicated they earned more money; 67 percent reported that the assistive technology helped them obtain employment in the first place.

What I would like is if you could—get me some specific examples. I would like to have those for purposes of enlightening those individuals who say these programs cost us a bundle of money. Again, it has been my experience in a lot of these cases that a one-time expenditure of money that looks like a lot of money to buy someone an assistive technology device saves us money in the end. It saves us money if that device enables that person to work and make an income, if it enables that person not to need paid personal assistance so much. I want to look at those trade-offs, so any example you can give me, I would appreciate that.

Mr. GANNON. Yes, we do have that for you, Senator, and we'll get it to your office this week.

Senator HARKIN. I would appreciate that. Thank you.

Dr. Hardy, you mentioned in your testimony that the private insurance industry may be reluctant to be involved in the systems change activities when the State insurance department is involved in the project. What we are trying to address in including these departments specifically in the legislation is the instances in some States where these departments have valuable information that the projects need, and cooperation has not been forthcoming.

We think that requiring the States to address how their insurance departments are involved in the planning and implementation of the project will give the State projects the leverage they need to get these departments to cooperate and share the information they have regarding the funding of assistive technology. Obviously, that's our goal. Now, if the draft language is not clear enough on that, or there are some problems that you see in that, if you could suggest some changes, or maybe some report language, that would clarify this and avoid some of the problems, we would appreciate it.

Mr. HARDY. I think that the provision that is in the draft that, if I recall correctly and I believe you quoted it, calls for each State to indicate how they have involved or contacted their insurance commissioner's office or whatever their office might be called, I think that would be a guide to the States that that type of contact and interaction is desirable.

We have made that contact in Iowa, and we were advised by that office that it would be inadvisable for them to be involved in what

we call our funding work group, where we have representatives of Medicare, Medicaid, the vendors' association, and others that are intricately involved with the funding issues. The insurance commissioner advised us that that office should not be directly involved, since it would be "frightening" to the 3rd party health payers in Iowa to have that regulatory agency involved in those discussions.

So I think the provision is satisfactory as long as it is not interpreted that the direct involvement and collaboration with that office is mandatory.

Senator HARKIN. Dr. Hardy, again, we are trying to see how we can get the private insurance industry involved in this. There is a great resource of funds there.

Mr. HARDY. Certainly.

Senator HARKIN. And I have had personal discussions with leaders of some large insurance companies, who might want to look at this. And since it is the State insurance commissioners who have jurisdiction over them, and who talk with them, meet with them on a daily basis, and have regulatory authority over them, we thought that by involving the insurance commissioners, it might help us to avoid some of the problems that the witness from Minnesota was talking about in terms of having this myriad of forms and myriad of access points and so on. Maybe if you had one form, for example, that type of thing might help to make it easier for consumers. We are not saying that you have to do this. I don't think our bill mandates that. We ask for a description of how they are involved.

Mr. HARDY. Right. And as I said, Senator, as long as that is not interpreted that it must be an active collaboration in which these offices are forced to try to work with the State grants and work to move the system too aggressively—as I say, I am one of the State that did contact that office. I believe the Minnesota STAR program has also contacted their insurance office. And I think it is just an issue that we must approach with care.

However, I would also say, to be candid with you, that our involvement with the private sector insurance companies that provide reimbursement for health care costs, long-term care costs, etc, are woefully unresponsive to the needs that we are talking about today.

In the preparation of Iowa's application, Iowa being one of the major insurance-writing States, I spent a considerable amount of time talking with representatives of some of the major companies in Iowa, with at least one goal—that we could provide their case managers with training that would reduce their costs of injured workers and get them back into the workplace more quickly, when otherwise, without technology, they would not get back at all.

And I must be candid that I believe that despite some protestations to the contrary, that particular industry has a long way to go to fulfill its avowed principles of humaneness, because I had the very definite impression that all they are interested in is the bottom line. So we didn't get to first base with those training programs that we were offering.

Senator HARKIN. Well, I think you could make the argument that you are trying to help their bottom line.

Mr. HARDY. That's what we were saying, but unless they can see it, and you can project it—one of the things, personally, that I think we are badly missing is hardcore data on the cost-effectiveness of assistive technology. You just asserted that reducing care costs, getting people back to work, and so on, is cost-effective. We need hard data so we can go to those insurance companies and say, look—

Senator HARKIN. Well, the Council has some data on that, and that's why I asked for some specific examples. But I don't know how big of a pool you looked at to get your percentages.

Mr. GANNON. We studied nine States and had public hearings in three—Maine, Minnesota, and California.

Senator HARKIN. Dr. Hardy, did you know about these figures that they had, the percentages and so on that they came up with?

Mr. HARDY. No, I did not.

Mr. GANNON. We'll make it available, Senator.

Senator HARKIN. Would you make sure that Dr. Hardy gets that, too?

Mr. GANNON. Yes.

Senator HARKIN. I'd appreciate that very much.

Senator HARKIN. Ms. Simpson, you raised the issues of trained professionals and training programs, and that there is a real shortage of professionals who are knowledgeable in the area of assistive technology devices. Would you see this as a priority area for the tech projects, having training programs for the professionals to get them up-to-speed?

Ms. SIMPSON. Certainly. CCD spent a great deal of time discussing this issue. We saw it as one of many priorities. Definitely, professionals need to know more about assistive technology and be more consumer-responsive.

To mention an insurance situation that I was in, I had double funding. I had 100 percent insurance support for an item of assistive technology for my child, but the professional would not sign off on the item because she did not think he was ready for it. So there is obviously a need for training for professionals to understand when consumers have a demand for something that maybe some of their training is getting in the way of the individual's needs.

Senator HARKIN. Thank you all very much for being here today. I appreciate it very much.

I want to state for the record that Linda Hinton has worked very hard on the tech bill and its reauthorization and she will be leaving us on August 1st, so you may not see the end result of what you worked on here. You will in the field, though, Linda, and I want to thank you very much for all of your help on this.

Senator HARKIN. Our fourth panel consists of Lee Graber, president of Capability Teaching, in Chicago, IL; Sue Swenson, from Minneapolis, MN, and Debra Turner, from Columbia, MD, accompanied by Nancy Weisenmiller, a team leader from the Kennedy Krieger Institute University Affiliated Program in Baltimore.

And I am delighted to have with me my friend and colleague from Minnesota, Senator Paul Wellstone.

Senator WELLSTONE. Thank you, Mr. Chairman. Let's go right in and listen to the panelists, absolutely. It's much more important.

Senator HARKIN. We are now going to be discussing the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. Again, I thank the panel for being here, and we'll start with Lee Graber, President of Capability Teaching, Chicago, IL. Lee is the owner of a small training and consultation company that provides training in values and attitudes about people with disabilities. They work with community programs and focus on direct care staff who have direct contact with individuals with developmental disabilities. Lee is also the father of a young man with disabilities and the foster father of a young woman with disabilities.

We welcome you here, and again, as I said, all of your testimonies will be made a part of the record, and if you could please summarize what you want us to go away with.

Lee?

**STATEMENTS OF LEE GRABER, PRESIDENT, CAPABILITY TEACHING, CHICAGO, IL; SUE SWENSON, MINNEAPOLIS, MN; AND DEBRA TURNER, COLUMBIA, MD, ACCOMPANIED BY NANCY WEISENMILLER, TEAM LEADER, KENNEDY KRIEGER INSTITUTE UNIVERSITY AFFILIATED PROGRAM, BALTIMORE, MD**

Mr. Graber. Mr. Chairman and members of the committee, I thank you for the opportunity to do this.

I like the way you threw in there, a "small" company. I like that. We are doing some national stuff throughout the country. The company is basically dealing with the valuing of an individual—identifying and developing the value in, not the value of, an individual.

I am the parent of a child with a disability. I have been messing with the system for a long time. I have been to IHPs and IEPs, and IPPs, and all those "P" programs they've got out there for us, and I came away from there knowing more about my kid's disease than I did his healing. I knew more about his disability than I did his capability. And I knew more about his limitations than I did his liberation.

And then after a while, as a parent, I had to step back and ask, what kind of a system is it that would more clearly define what is wrong with somebody than what is right with somebody?

So I just proceeded to see what works and what doesn't work, and what works is valuing. If you value a person, they can learn. Everybody can learn. They will learn within their capability and within their life flow experience. They will learn by taking concepts and imaging those concepts. But everybody can learn. So we are not dealing with "some people can learn, and some people can't."

My mother always taught me when I was a small child that it wasn't the mixture of my blood that mattered; it was the content of my character and the excellence of my spirit and the honesty of my path. And then I grew up. Did I find those things not to be true? No—just not to be practiced, that's all. They are just as precious as when my mother taught them to me. But you see, I realized right off the bat that that is real people stuff, real people stuff, to be identified and developed. And I think that my child has a right to the opportunities of that real people stuff.

It is not the Act. The Act is wonderful. The principles are wonderful. It is the action. It is the implementation. How do you trans-

late something that is marvelous in concept; how do you image that concept so that it touches that individual's life out there?

I was in an institutional setting talking to a 60-year-old woman named Flossie. Flossie was a neat lady. Flossie was working in a workshop, and I asked her, "Flossie, what do you do in your workshop?"

She said, "I make buttons."

I said, "Oh, wow. Do you like doing that?"

"I like doing it."

I said, "If you could have any job in the world, Flossie, what would you like to do?"

She thought for just a few seconds, and then she said, "I'd like to make badges." The same workshop, a couple of work stations down.

There is a phrase that we use in class all the time: Take what you can get closest to what you want—because we build on what people can do, not what they can't do. I'll take it, Flossie; I'll take it.

I said, "Flossie, how come you didn't tell anybody about this?"

Flossie said, "Nobody asked." Nobody asked. You value people. You are relentlessly searching for the capability in someone. A quick example. A wheelchair was never built for a disabled person. It never was. It was built for a capable person who couldn't walk. It gets you from point A to point B so you can develop your capability and then get on with your life. It is a tool, not a lifestyle. Human services made it a lifestyle, because we have devalued the individual using the chair, and instead we refer to them as the individual in the chair. It is value base.

I find myself walking down a hallway behind a client—consumer, individual, whatever you are going to call that person depending on what area of the country you are in. He is living in a group home, in a configuration like that, and he is taking me back to show me—it can be a man or a woman, it has happened hundreds and hundreds of times in my career—they are taking me back to show me their bedroom. Why? It is the only place of ownership they have.

I had a lady in an institutional setting, a dormitory, where she roomed with 19 other people, and she showed me like a rollaway bed and cardboard box at the bottom of the bed, and she was excited about it. She showed me, and she said, "Lee, this is where I sleep. This is where my stuff is." And what I saw was what was in her eyes, and what was in her eyes was ownership. She owned something. She took ownership over that.

Education looks at the value base, and it gives people ownership over their thoughts and their feelings and their dreams, decision-making, problem-solving, making value judgments, discerning between what is better and best for them, preferences, things that irritate them, things they love, things they dislike.

And this lady is looking at me, and I see all this kind of ownership. Our responsibility is to give her ownership over something more than rollaway bed and a cardboard box; to give her ownership over her life, because that's what it's all about.

Education is a discovery process. Education comes from the inside out, not the outside in. Education is the presence of something in someone's life, not the absence of something. Education is the re-

lentless search for capability, and how we define the teacher—the most marvelous thing in the world is one human being assisting another human being to discover the value inside himself. That's a teacher. That is a teacher. I don't care what subject you teach, I don't care where you teach or whom you teach or how much IQ is there. That has nothing to do with it. If you value that person, and that person sees the value inside himself, that person will do better at that subject because that's the name of that tune, and that's what it's all about with teachers.

There is a Pawnee saying that says: Remember the circle of the sky, the stars, and the brown eagle. Remember the life of the sun. Remember the young within the nest. Remember the sacredness of things. This is what we have our hands on, is the sacredness of things, not a left brain linear approach that goes in one direction, but a holistic approach that enables a person to see a life, an opportunity. It gives them hope, and the definition of hope is to cherish a desire with expectation of fulfillment. "Hope" is a proactive word. It isn't something you sit around and wait to happen. You make it happen.

You prepare people for their opportunities by developing their capabilities. I don't care what my kid can't do. I don't care. Let's find out what he can do, and we'll put his life together, give him a life, give him direction, give him something holistic he can work at and build and grow and develop and become as interdependent as possible. And that's exactly what I did. If I can't do it with my own kid, then I shouldn't be telling you anything. It just works. It just really works.

My mother also taught me when I was small that my life was seeking after the fire of my spirit. The fire of my spirit wasn't a light that I saw; it was more than that, because as I drew close to the fire of my spirit, I stepped within the circle of light reflected from it, and I was told not to be too arrogant there about how much I knew—but step closer, and reach out, and feel it. And what you felt was the heat coming off the fire. You can't just have the light. You've got to have the heat. And the heat is the passion. Passion for whom? For the thousands we serve. That's a bunch of nonsense. For the one person we serve. If we can serve one with quality, we can serve ten, and 100, and 1,000 and a million, whatever.

We start out the other way around too often, and you've got people who have the Act out there, it's beautiful, it's wonderful, it's solid, and they ask how can we serve these thousands, instead of asking how can I serve this one and touch that one.

This is a healing process. There is a lot of healing going on in people, in families. How can I serve the one individual? How can I serve the one family? How can I do these things for that person? How can I make that difference?

We are educators, all of us. We are students, we are teachers. And we are constantly reaching out, and we are constantly receiving.

One of the primary, basic—and it is not an oversimplification—in order to make the Act work, people have to see themselves out there as sponges and fountains, not just listening to people but experiencing people. And what you take in builds a reservoir inside you. And it is a reservoir not of tolerance, but of understanding. I



tolerate mosquitoes because I can't do anything about them. But I seek to understand people, because that's how we do this.

So we build that reservoir of understanding now, and it is an opportunity for us to be a fountain and touch an individual's life out there. We have the substance to do that. But it all begins with one person. One person.

I walked down the hallway with John so he can show me his room. We got back there, he opened the door and turned the light on. The place was a mess. It looked like a war zone. John wasn't going to be riding on the retarded bus later, going out to get a snow-cone or something. No, because he didn't meet the criteria. So I talked to John a little bit, and I asked, "Hey, John, does anybody help you take care of your room here?"

And he said, "No. I'm by myself. I sleep here by myself." Proud. Ownership. This is mine. He had to jump through a million hoops to get there. So he said, "It's my room."

I said, "That's not what I meant, John. Does somebody come in and help you make your bed and clean your floor and your closet?"

"No, they don't, Lee. They do not, Lee. They don't. I do it myself."

The next thing out of my mouth, I said, "John, this room is excellent."

The problem with taking the Act and the marvelous work you've done on that and translating into real, live spirits, is you have to understand that excellence is not perfection. Excellence is effort. It is the best a person can be and do at any juncture in their life. And how you make the Act work—you take that person at that time, and you build on it. That's all you do.

I appreciate it. Thank you very much.

[The prepared statement of Mr. Graber follows:]

#### PREPARED STATEMENT OF LEE GRABER

Mr. chairman and members of the committee, my name is Lee Graber and I am the founder of capability teaching, a national organization focused upon influencing a value-base, centered upon individuals and families. I appreciate the opportunity to speak to you today to as a parent of a capable man with disabilities—as a foster parent of a lovely young lady perceived trapped within the barriers of a laundry list of labels—and as a professional with exposure and consultant with agencies in the majority of States throughout the country.

The values principles proposed within the preamble for this significant act clearly represent the expectations our country places upon valuing individuality and the capacities or capability of each person, including persons with developmental disabilities. The principles recognize and influence one's potential opportunities and contribution to the social and economic fiber of our society.

While these words establish an essential foundation, the traditional and common practice in service systems continues to be centered upon limitations and deficits. We are rampantly developing behavior programs—creating aversive or restrictive strategies to extinguish unacceptable traits of an individual and—facilitating interdisciplinary teams that craft plans based upon limitations. Persons served and their families generally leave these meetings having learned what one can't do—rather than what one can do—more about the disease than the healing—more about the disability than the capability and more about limitations than liberation.

These practices bring the integrity of valuing into question. One must assess how we are perceiving a person with developmental disabilities? Do we acknowledge them as an individual with a personality—with thoughts and feelings—as one who can do things? Do we pursue our oneness with him or her, or do we dwell upon their difference?

Solid valuing practice occurs within services and supports when we relentlessly pursue one's capability and nurture it's growth. The fertile ground for this growth is created within an atmosphere of education and upon a foundation established by an individual discovering his/her identity, dignity and self-worth. Those individuals

with the most direct contact with capable persons must become skilled teachers who empower their students with the tools to influence and manage their lives. The reference to "teacher" may encompass a wide range of individuals—the family—the school professional—the direct contact staff. The teacher touches this student as a laser and connects him or her with who they are and what they can do. The teacher and the student begin creating the mosaic of this valued person's life—bit by bit. Piece by piece revealing capability and perceiving the evolving glimpses of a rich and full life.

When individuals learn what they can do, they move their limitations. as a service provider considers this statement they may respond by stressing, "but in our program, we focus upon strengths—we identify a list of needs—and we truly care for our clients". Teachers through capability teaching would react that if we focus upon strengths, those identified may not include the evolving capability or seeds for growth—rather than needs being identified we must concentrate upon the development of options and choices that influence growth—and caring should not be the operative word—it's how we care—that's the issue. One does not need to be cared for—one needs to learn to care for themselves.

By applying the concepts of capability teaching, the teachers and the guidance systems of management and service coordination utilize the discovery process to explore and reveal the preferences, likes, dislikes, fears and dreams of an individual. The results yield elements of the persons life that they can influence and change, windows of teaching and learning and inclusionary opportunities. The team proceeds with the process by evolving a fluid plan, affording options and choices based upon the identified capability and within the natural life-flow of the individual. The goals and objectives outline expectations of education rather than incorporate reductions in inappropriate actions and reactions.

The teachers proceed as within the application of an art form to mold and shape opportunity as the individual is liberated from the boundaries of disability and labels. Teachers are responding in a holistic manner to this multi-faceted individual as they continue to develop through exploration and exposure to a new menu of life. We have placed "do's" rather than "don't's" in his/her life. We have witnessed grow within capability and moved the limitations. We have influenced behavior rather than controlled or managed the individual's life. We have enabled the person to be become empowered with the skills and tools to assume ownership and responsibility. value is no longer reflected by words yet becomes a reality in the life of this "real" person.

Through the focus upon capability, we nurture and include the family. They move from the posture of apologizing for their child and relish in their opportunity to participate in the growth and the healing process. They attend a team meeting finally recognizing who their child is and what he or she can do. They are afforded the opportunity to visualize and support the child into phases of transition toward adult life.

The picture of the valued person begins evolving:

- Baby boy Foolscrew
- Little Davie Foolscrew
- Dave Foolscrew
- Mr. David Foolscrew

These stages and perceptions of transition become reality. The person and those in his/her life begin to discover the value from within, based upon:

- content of character
- excellence of spirit
- honesty of path

The transition of Mr. David Foolscrew from birth to the adult man is realized by the lessons and experiences of his past. The present has evolved as his creation and he assumes ownership of the content and direction of his path. the future becomes his inspiration—as he can now glimpse the total picture of his journey which he can influence in course and quality.

Senator HARKIN. Very good, Lee. That was very motivational. I could listen to you for a long time. That's good stuff.

Next, Sue Swenson, who is a parent of a son with developmental disabilities from Minneapolis. After participating in a special intensive training program designed to promote consumer empowerment, she has effectively advocated for her son and helped other families do the same. In addition, Sue was one of only 10 par-

ents or consumers nationally to be trained as a member of peer review site visit teams for the University Affiliated Programs.

Welcome, Sue. Please proceed.

Ms. SWENSON. Thank you, Senator.

Senator HARKIN. Gee, you have both your Senators here. How about that?

Ms. SWENSON. Yes, I do—and I was on the plane with Senator Wellstone yesterday. Not only that, I was on the plane with Senator Wellstone yesterday and last year when I came out to be trained to do the UAP thing.

Senator HARKIN. You must be on the same schedule.

Ms. SWENSON. I was not able to bring Charlie with me today, but I brought a couple of pictures of my boys which I would like to show you. The doctor won't let me lift Charlie anymore. He weights about 90 pounds. The doctor hasn't come to the house to watch me carry him upstairs, however, but we don't invite him to do that.

Mr. Chairman and members of the committee, my name is Sue Swenson, and I live in Minneapolis, MN with my husband Bill and our three sons. Will is 13, Charlie will be 11 in August, and Eric is 5.

I grew up in Red Wing, MN which, as the Senators from Minnesota know, is just around the corner from Lake Wobegon. I went to school at the University of Chicago. I have a supportive family and a good education. And I thought that would prepare me for being a good parent, and I certainly expected to be a good citizen.

As it turned out, the DD Act and a program sponsored through the Minnesota Governor's Planning Council on Developmental Disabilities made more difference to my family than anything else.

When Charlie was first identified as having the kinds of disabilities that he has, I didn't know anybody who had any ideas—including my sister the doctor and my sister the nurse and my other relatives who are teachers—I didn't know anybody who had any ideas that could help me deal with the reality of raising a son who probably couldn't walk or talk and probably could not see very well, either.

My husband and I worked very hard on Charlie's therapy, silently hoping that he would get better so we could get back into the real world that we felt we had been sort of kicked out of. I went back to school to get an M.B.A., because I thought we were going to need more money. Those days were pretty grim, even for Scandinavians. [Laughter.]

I wanted to mention, too, that Charlie uses a McIntosh "Power Book" to communicate, and the voice synthesizer sounds so funny that he has programmed it to say: "My computer is Norwegian." [Laughter.] I loved listening to Rachel's; it was just terrific.

By age 5, Charlie was in a segregated school, in a segregated room for children with multiple disabilities, all the way across town from our house, because I thought that program was going to make the most difference for him. His teacher slipped me an application to Partners in Policymaking. I applied and was accepted to the class, which started in January of 1989.

Partners promised to give me skills that I could use to help me understand Charlie's needs and the programs that would help him, and to help me get access to those programs. Partners in Policy-

making in Minnesota trains about 30 people a year and has since 1987, parents of children with disabilities and people with disabilities. The program has now been picked up in 20 States around the United States, and 1,200 people have been trained so far. This year, we trained 14 more States. I was part of that training session in Texas. So now there are 34 States. Whether it is a DD council or a UAP, there are many different organizations running the programs, but there are that many out there.

At Partners, my 30 classmates and I were exposed to national leaders who told us what was working. We learned the history of the disability movement, something that was brand new to me. We learned the history of the parents movement, and we learned about People First. They told us what they were working on and what you were working on. These were the days when ADA was coming down the pike, and it was very, very exciting for us.

They taught us to use People First language. They challenged us to find our own path, our own beliefs, our own values. They told us about using technology, about supported employment, about independent living. Remember, these things were all brand new to me at that time. It was like drinking from a firehose sometimes; that's how I describe it.

We learned to participate in the policymaking process, how to work effectively with professionals and government officials. We learned how to run a meeting and supposedly how to give testimony—you tell me how I'm doing.

We learned that when it comes to our lives, we are the experts. When it comes to our kids, we are the experts. We met 2 days a month for 8 months. Somewhere in there—I don't remember exactly when it was—I came home and said to my husband, with great relief in my voice, "It's okay, honey. We don't have to work so hard to change Charlie anymore. All we have to do is change the world." That was a tremendous relief. It is easier to change the world.

We are still struggling with Charlie's services, which don't really support our family as a family. And by the way, if you are ever talking about services, I would be very happy to come back and talk to you about that. In the 4 years since I graduated, Charlie went from that segregated classroom within a segregated school to an inclusive classroom in the same school that his brothers attend.

We had to build an elevator to do that. We had to change a lot of people's minds. But I haven't sued anybody yet. It has been very much a partnership. It is very much a process of going to people and explaining what you need, why you need it, and things just happen.

Charlie's classmates voted him "most popular" at the end of this year. He is making friendships in the class, which I think is the most important thing. I have a note here from a boy that came home in Charlie's backpack on the last day school. There is his phone number up on top. It says, "Charlie is the coolest kid. I have learned a lot from Charlie. We played at recess. We talked. I really like Charlie. P.S. I would really like to come over. I know you say I can just call, but my mom says I can't—you have to invite me." About half the words in this note are misspelled, which to me was

a tremendous comfort, because it meant that a grownup didn't write this note for him; he wrote it himself.

I really want to say I think Charlie is making the difference. Inclusion is the right way to go, because the kids who are going to school with Charlie today won't grow up—if they have a child with a disability, they won't have the kind of negative images and lack of information that I had when I became the parent of a child with a disability.

As for me, I have served on a bunch of boards and advisory groups. Last summer, I was trained to do site reviews for University Affiliated Programs. My team reviewed Minnesota last fall. My career is in managing and organization of professional services organizations. Right now, I work with 250 consulting engineers—speaking of linear thinkers.

The review process was a very interesting exercise, particularly because of the lack of customer satisfaction-driven accountability systems—something in engineering that we have to do now just as a matter of course. I believe that the draft of the DD Act which you have before you would be strengthened by replacing any references to compliance-based accountability systems with consumer satisfaction-based systems.

People with disabilities and their families should not be left out of the consumer revolution. People with disabilities and their families have opinions, wants, purposes and needs, which should be the basis of improving and changing the systems which serve and support us.

In Minnesota, there have been 7 years of Partners and 7 years of data collected longitudinally on all of the participants in Partners—how did you like the program? What was useful? What did you use? How would you suggest it be improved? I think this is the tremendous strength of that program in Minnesota.

Thank you for the opportunity to be here today.

[The prepared statement of Ms. Swenson follows:]

#### PREPARED STATEMENT OF SUE SWENSON

I live in Minneapolis, MN with my husband Bill and our three sons: Will, who is 13; Charlie, who will be 11 in August; and Eric, who is 5. I was the third generation of my family to grow up in Red Wing, MN, which is just down the road from Lee Wobegon. I went to college and graduate school at the University of Chicago. I thought my supportive family and good education made me ready to be a good parent. As it turned out, a program made possible by the Developmental Disabilities Act made more difference than anything else. I want to tell you my personal story of empowerment. Because of the DD Act there are many other people who have stories like mine to tell. I could try to give you numbers, but I couldn't dream of telling all the stories. I think the personal impacts of empowerment are greater than the numbers might show.

Ten years ago when Charlie was 9 months old, his pediatrician first acknowledged that he had severe and multiple disabilities. I was pretty sure that the bottom had dropped out of my life. No one I knew had any ideas that could help me deal with the reality of raising a son who probably would not walk or talk, and who probably couldn't see very well, either. Like me, they had no meaningful or positive experience with people who have disabilities. My experiences were typical of the times: I knew very few people with disabilities and no people with severe disabilities. Carl, a boy who I now know had cerebral palsy, was in my kindergarten class. Our class had saltines from the cafeteria when it was Carl's turn to bring graham crackers because his family lived in poverty. At 5, I thought his problems were caused by his family's poverty. The families who could afford graham crackers had no children with disabilities in the schools when I was a child. Carl and his brother drowned in the Mississippi River when they were 7 and 8 years old after Carl fell in and

his brother jumped in to save him. My childish theory was that even mild disability ended in tragedy. My sister Barbara and I sang at the boys' funeral, and we also sang Christmas carols at the local State Hospital. I remember standing one Christmas at a locked door at the end of a long, green hall, seeing people's hands reaching out through bars in their doors as we sang. Later, in high school I knew Don a little bit. He was a big, strong friendly boy in my class. He scraped everybody's uneaten school lunch into the garbage every day, wearing a big rubber apron. I guess that was his job training, but it was a very tough job to do with any dignity. He never looked up while he was working. Over the years I collected the usual images from the movies like "The Miracle Worker," which taught me that good strong people can fix anything if only they never give up. If you add to that a few quick channel changes through the ridiculous telethons and a few passing glances at those ads offering a "loving environment for your handicapped loved one" in the back of magazines and some men panhandling from wheelchairs in downtown Chicago, you have about exhausted my whole experience with disability before my son was diagnosed.

I wish I could say we faced the challenge of our son's disability heroically, but we didn't. I spent whole weeks crying. We listened to all the pity and the platitudes, which only seemed to make things worse. We struggled. We couldn't find anybody willing to care for a baby with disabilities, so one of us had to be home all the time. As time went on and Charlie got bigger, we avoided taking our boys out, even to the park, because we couldn't cope with all the prayers, pity, stares, and outright hostility we encountered. We worked very hard on the therapies, silently hoping that Charlie would "get better" so we could go back to the real world. I went back to school to get an MBA, my second master's degree, so Bill and I could share the responsibilities of taking care of Charlie and making money in case Charlie didn't get better. We were pretty grim, even for Scandinavians. I remember that time as one long black-and-white Bergman movie.

Four years later, during the 1987-88 school year, Charlie was going to school in a segregated classroom for children with multiple disabilities inside a segregated school for children with disabilities, all the way across town from our house. This was the placement recommended to me as "the program we have for children like Charlie." I did whatever the "experts" told me to do, in the hopes that it would help, but I couldn't help asking questions. Halfway through the year, Charlie's new teacher, Cathy Carr, slipped me an application to a program called Partners in Policy-making which was offered by the Minnesota Governor's Planning Council on Developmental Disabilities. She told me it would be good to get some answers to my questions. I had to promise her I wouldn't tell where I got the application because there were several lawsuits about placements and a lot of tension in the school and she didn't want to be labeled a troublemaker. She knows how grateful we are that she took the chance. We laugh about it now. The application required a commitment from me, that I would attend all the sessions and do the homework. In return, I was promised a free, intensive program that would give me tools and access to ideas.

At Partners, my 30 classmates and I had a chance to get to know national leaders like Ed Roberts, Ian Pumpian, and Lou Brown and real moms like Fran Smith and Betty Pender who told us what was working out there. They told us how they felt and what they thought about disability. They taught us to use people first language. We learned the history of the disability movement, from the parents' movement right up to People First. They told us what they were working on. We learned about independent living, supported employment, and family support. We learned how to use assistive technology and how to access the human service system. We learned about personal futures planning and whole life planning.

We also learned what Congress was working on. They told us about the ADA. They helped us sharpen our vision of living in a world with no restrictive environments. They challenged us to find our own path, our own beliefs, our own commitments.

We learned how to participate in the policymaking process and how to work effectively with professionals and public servants. We learned that we were the most reliable experts about what our kids needed, and about what we needed if we had disabilities ourselves. We learned how to run a meeting, how to testify, and that we should testify. After a tough college and two master's degrees, it was the toughest learning I ever did, because it was so real and so important to me and to my kids.

In those 9 months, we came together for two days each month and worked on homework in between. I remember realizing at the first session that there were responsibilities that went along with all this learning. It was a new idea to me that there was or ever had been a civil rights movement among people with disabilities. I don't remember how it happened, but slowly I became aware that I was no longer

working on fixing Charlie so my family could "go back" into the real world: now I was working on changing the attitudes of all those ordinary people, so they would see the value of communities which include people with disabilities and all people. I was working to help my friends and neighbors see that we all live in one world. It is important to me to see to it that other children wouldn't grow up as I did: removed from any possibility of understanding the variety and richness of the human community, left without the ideas I needed to deal with disability in my own family.

In Partners, I learned that I could stop trying to make Charlie into somebody he wasn't. I went home from one session feeling as confident as I've ever felt, and told my husband, "Don't worry, it's okay, we don't have to change Charlie. We just have to change the world." Now, I know I can't change the world alone, and Partners doesn't teach people to think you can do it alone. Instead, Partners empowers people to do their part to change the world and make it more inclusive.

In Partners, I learned that the way to change the world is to focus on what you need to live your life, to speak up, and to participate. We learned to be secure in the belief that we were the best experts on our own needs. We learned that people need to be in charge of their own lives, even if they happen to have a disability or a child with a disability.

Because I say that everyone should be included and that self-determination is possible for people with severe disabilities, some people have called me a radical. If it is radical to believe in the principle of self-determination, then I am a radical. If it is radical to be suspicious of the opinions of experts who want to tell me what is best for my family, then I am radical. If it is radical to think my son should be in charge of his own life, then I am a radical. Viewing experts with suspicion is an American tradition. Devotion to self-determination is an American tradition. Belief in the dignity and value of the individual is an American tradition. So perhaps I am a traditional American radical just moving on to the last great inclusion of American life.

I sometimes think that Thomas Jefferson would be happy to know that the principle of self-determination is still considered radical by some Americans after 200 years. Jefferson's fruit of revolution continues to ripen on the tree. Perhaps revolutions in families and schools and communities are quieter revolutions than Jefferson knew, but they are no less real. Since reading Joe Shapiro's *No Pity*, I have begun to quote T.J. Monroe on the subject. He said: "This is a free country. You can talk for yourself. You might need some help, but you can talk for yourself." That seems like a fine traditional American radical sentiment to me.

In Partners, I learned to speak for myself and for my family. I learned to listen to Charlie better. First, I learned to ask for what we needed to keep Charlie living with us. A month before I graduated from Partners, Charlie got enough personal care attendant services to allow him to have some independence from me and to allow me to work full-time. A few months after I got the job, my company's health insurance bought Charlie's power chair. Our family isn't falling off the edge anymore and we hope to be able to send our sons to college. (I have always said that a fraternity house will be Charlie's only experience with a group home.) We're still a little groggy some days after Charlie has been awake for several hours in the night, as he is about half the time, and now we need an elevator in the house. Charlie still lives with us and generally we are all doing very well, even though the problems go on and change. (I would like to ask to be invited back when you address the delivery of services and supports.)

In Partners, I also learned what went into a good educational program. In the last four years, Charlie has gone from a segregated school to a segregated room at his brother's school, to part-time inclusion, to full inclusion. In 1989-90 I negotiated for 10 minutes of inclusion during story time after lunch in a second grade down the hall from the "special" room. After a week, the kids insisted that he didn't want to go back to the "special" room, so he stayed all afternoon from then on. The next year, he was included full time in that second grade, and the year after that we completed an elevator which allowed him to move to a fourth grade with his age-mates. Last year, his collaborative team (including teacher Susan Bell, paraprofessional Mike Alexander, special resource Carol Kramer and speech teacher Ann Davis) and his classmates introduced Charlie to facilitated communication, which allows Charlie to communicate by spelling with facilitation from another person. This year, he is included in a fifth grade where he is doing math at a fourth grade level. He reads pretty well if the book is held upright in front of him, and answers questions about what he reads. When I asked him what communication meant to him, he spelled "power." When I asked him what kind of power, he spelled "touch" and "kognutiv." Later, I realized he meant "cognitive," a word he has heard for years. His spelling has been phonetic, but he is learning to spell better. He reads music well enough to recognize simple scores when he hears the music played. He recog-

nizes composers. He doesn't cry and yell all day like he did in the segregated room. If you ask him how he learned so much, he tells you "by listening." He also will tell you "I am a very smart boy." He is proud of himself. He won the wheelchair race during field day last month, and one of his classmates complained that it wasn't fair because he got to practice all the time. She didn't even mention his electric motor. His classmates voted him "most popular" at the end of the year, and he is developing friendships with other kids both inside and outside of school. The friendships are the key, what it is all about for us. Sustaining the positive force of friendship in Charlie's life is our real goal. I want to share with you two notes that were in Charlie's backpack on the last day of school. One from his teacher, Mary Lou Hoff:

"Dear Bill and Sue, Just want you to know how much I've enjoyed getting to know Charlie this year. Despite some initial doubt and skepticism, I can't begin to tell you what a powerful experience it has been for me both personally and professionally. Charlie's presence has had such a positive impact on all of us. As he and his classmates have interacted throughout the year, I have seen relationships develop and grow on a level I wouldn't have thought possible in September. I'm sure I speak for all of us in 204 when I say Charlie has touched us deeply and we are the richer for it. Thanks for the commitment and support."

And one from Charlie's new friend, David Ribble:

"Charlie is the coolest kid I have learned a lot from him. We played at recess, we talked. I really like Charlie. p.s. I would really like to come over. I know you say just call but my Mom says I can't call you have to invite me."

The spelling is my favorite part. It shows there was no grownup coaching him.

There are lots of good people out there—policymakers, bureaucrats, academics, other parents, kids, neighbors—who want to do the right thing. They may need to hear what the right thing is a few times, and why it is right, but after they get it they dive right in. I was taught to challenge people, to help them understand, to show them a new way of thinking about people with disabilities. For people with disabilities, change really happens in their schools, neighborhoods, and families and in the hearts of all these fine and ordinary people. As Joe Shapiro points out, Congress can sponsor this change by giving us the ADA, the DD Act, and IDEA, but we must take it to the people, one by one, before the real changes happen.

When the change to inclusive thinking starts, it is amazing to see. Now sometimes I just stand back and watch. I worked for two years to get an elevator in the school, but the next year the principal decided to close the segregated classroom without more than a hint from me. All the kids are included now, and new applications arrive constantly. Parents of typical kids are requesting inclusive classrooms because the atmosphere is one of collaboration and belonging. In Minneapolis, parents choose their child's school, and Charlie's school, Fulton School, is now one of the most popular elementary schools in the city. Our new principal Frank Hinkle was also new to inclusion last Fall, but now he is spearheading a city-wide inclusion Task Force—120 people came to the first meeting, representing 30 schools. Our next meeting is June 30 and we expect even more people. There are 43,000 children in the Minneapolis Public Schools, 5,000 of them with IEPs and we're working on full inclusion district-wide. We are guided, as we ought to be, by the principle of 'no restrictive environments' set out in the ADA.

I haven't sued anybody, and I haven't used a professional advocate. Maybe I was lucky, or maybe the system responds better to people talking for themselves, and focusing on creating partnerships. For my family, achieving inclusion has not been an adversarial process. Now, I know there is just no way I'm changing that school district to be inclusive by myself. But I am a full partner in the process, and only because of Partners.

Since graduating I have served on several boards and committees, including my local ARC, the state and local Special Ed Advisory Committee, and Fulton School's site-based leadership team. I have also participated in training sessions for other states preparing to offer Partners programs. I have also been trained by the Administration on Developmental Disabilities to be a consumer reviewer of university-affiliated programs. I helped review the Minnesota UAP last September. They said then that they welcomed my challenge to be responsive to the needs of their chain of clients, and to the end user. They want to be more accountable for outcomes, instead of for compliance with pre-set standards. They want to try new ideas, but they also want to have a way of knowing whether their ideas are doing any good. By the way, I attend my first advisory committee meeting at the UAP's request on June 28th, so whether they liked what I had to say in the review or not, they're in for a lot more of the same.

Of course, some of the academics in Minnesota and around this country know the truth already and they don't need any consumer's opinion of the usefulness of their



theories. Certainty comes with the territory. (My husband is an academic. Some of my best friends are academics.) I believe that the DD Act should encourage academics at UAPs to demonstrate that they understand their mission is to train people to teach and work with people in the next few decades, not in the previous few decades. Which to me implies that they need to be developing new ideas, not promulgating old ideas, or safe ideas, or esoteric ideas. They should not have to worry so much about appearing foolish if they try something that can't be proven valid beforehand. Felix Cohen said in his essay "Indian Self Government":

"Of course, we must all start with the assumption that we are right or as near right as we can be. But can we not also recognize, along with Justice Holmes, that time has upset many fighting faiths, and that even if we are possessed of absolute truth it is worthwhile to have somebody somewhere trying out a different idea."

Everywhere I look—in business, environmental programs, health care, and education, I see organizations using continuous quality improvement principles and customer satisfaction measurements to improve what they do, to guide the development of new ideas, to keep them on track. But I don't see accountability to clients, customers, and users in the programs supported by the DD Act. People with disabilities and their families should not be denied the opportunity to judge the effectiveness of programs intended to help them. As these findings make abundantly clear, disability even severe disability—does not mean people don't know what works for them, or what they want.

As Aristotle said in his *Politics*, the person who lives in the house is the best judge of whether the house is good—not the architect. Or from Felix Cohen again, "America, despite all the lingo of the administrative experts, has insisted upon self-government rather than 'good government,' and has insisted that experts be servants, not masters." As these findings state, our systems of support delivery are not yet responsive to the highly individual needs of people with disabilities and their families.

Therefore, I believe the draft before you would be strengthened if the systems which are responsible for innovation, systemic change, training, and information dissemination were made more accountable to clients, customers, and users. I do not see how they can help create more responsive systems if they do not measure and improve their own responsiveness along the way.

Partners in Policymaking, as conceived in the original Minnesota model, is responsive because it tracks outcomes over time by asking the participants what they think, what is useful, what could be strengthened, how the program could be improved. Empowerment and leadership programs are responsible to the people who have to go out in the world and use what they know. If Charlie and I had tried to do what we've done with less complete training, I think we would have failed. And we didn't need another failure. Paper wings wouldn't have carried us. We didn't need a support group or an information clearing house we needed a thorough education.

Organizations other than the Minnesota Planning Council on Developmental Disabilities are offering Partners. Many are excellent and effective empowerment and leadership programs for people with disabilities and parents of people with disabilities. I believe the draft in front of you could be strengthened by adding language which makes the responsibility to clients, customers and users clear to Councils and to any other organizations who offer empowerment and leadership training to parents and people with disabilities.

I work with professionals. I have worked for lawyers and doctors, and now I work for a large firm of consulting engineers. They are all using quality principles to guide their service improvements and their responses to their clients' needs, and to help them design their future services. Every organization with which I have ever discussed quality improvement begins by saying that it is a great idea, but would never work with "our" clients. Others say that quality is only for competitive environments, but I believe organizations in non-competitive environments need to go to extra lengths to make sure they are responding to people's needs.

I know there are hundreds and I believe there will be thousands of stories like Charlie's if the DD Act continues to encourage experimental, outcome-driven, change-making programs like Partners in Policymaking. Twenty states have completed training sessions modelled after Partners, and 35 states have been trained to use the model that was developed and tested in Minnesota. There are now 1200 graduates. I don't speak for them—they can surely speak better for themselves—but I have had an opportunity to meet some of the graduates at a Texas training academy for states interested in creating Partners programs. Partners can't help but make a difference, in each of their neighborhoods, cities, counties and states. It might take time. Empowerment begins in your own home, with your own family. People often need to do significant work to get their own support systems in place

before they can have enough control to be as involved as they want to be in policy-making issues. For my family, it took three years to get things lined up for Charlie, but last year I gave about 300 hours working on systemic issues. Some Partners still must struggle with finding transportation to the meetings they want to attend. When they get that solved—and they will—the pattern of empowerment, commitment, and determination will emerge.

I am now beginning to target "generic" organizations rather than special disability organizations, such as environmental groups, generic school advisory committees, and business organizations. Many Partners are well beyond that: some have run for office, several are planning to run for school boards, and some have spoken at international conferences. It might take ten years, but the impact of Partners will be felt.

The DD Act made these outcomes possible. As you continue and strengthen the purposes of the Act, please know that the Developmental Disabilities Assistance and Bill of Rights Act makes real and meaningful differences for people with disabilities and their families.

Senator HARKIN. Thank you, Sue. That was a very compelling story.

We'll hear next from Debra Turner. Debra is a person with a disability from Columbia, MD—so not too far away, right? Debra used to live in an institution and has now moved to her own townhouse in the community with the assistance of the University Affiliated Program and the Protection and Advocacy Program. Her life has improved dramatically.

She has a roommate who provides the support that Debra needs. And Debra is accompanied by Nancy Weisenmiller—and Nancy, I understand you are Debra's roommate?

Ms. WEISENMILLER. Yes. We have another roommate, also.

Senator HARKIN. OK. And Nancy is a team leader from the Kennedy Krieger Institute of Baltimore.

Welcome, and please proceed. We're glad to have you here.

Ms. WEISENMILLER. Thank you.

Debra is supported by the Kennedy Krieger Institute, which is a Maryland University-Affiliated Program. Debra is also part of a legal class called the Knott's class, which is represented by the Maryland Disability Law Center, which is Maryland's protection and advocacy agency. It was their advocacy that assured funding for support for Debra and over 20 other individuals supported by Kennedy Krieger.

From about the age of 14 until the age of 33, Debra lived in an institution for people with mental illness. With funding, Debra has been afforded the opportunity to move from locked buildings, no decision-making power, and no choices, to an individual living in a townhouse, taking G.E.D. classes, voting in the last Presidential election, and attending church each Sunday, which is her favorite thing to do.

It is interesting that when Debra moved from the institution—I have lived with Debra for 3-1/2 years since she moved from the institution, and Debra had a difficult time expressing wants, needs, and desires. And when it came to dreams, there was nothing there. Debra did not know what a dream was. And I think that's what 15 years of living in an institution does to someone. No one listened to what you said, so it didn't matter what you said; it didn't matter what you wanted.

Debra started learning all these things and learning all these activities, and she wanted to share this with people, but she had a hard time sharing it. And I think it is interesting that you are also talking about assistive technology, because what we discovered—

and I don't think people would think of a slide projector as assistive technology, but it definitely is for Debra, because it helps her to explain what is important to her, to have pictures and slides.

Debra has a whole slide presentation of about 65 slides, and unfortunately, she couldn't do all that today, but she did pick a couple that she wanted to share.

Senator HARKIN. Good. We look forward to seeing it.

[SLIDES.]

Ms. Turner. This is the Spring Grove Mental Institution where the mentally ill are at. I used to live in level 1 or 2.

This is me at my birthday party at Spring Grove.

Ms. WEISENMILLER. This was taken about 4 years ago; it has only been 4 years.

Ms. Turner. This is my townhouse on Majors Lane, Columbia, MD 21045.

This is me, dusting off elephants.

Senator HARKIN. It looks like you've got quite a collection.

Ms. Turner. Yes, a collection.

This is me, trying to get my homework done for my G.E.D. I go to school twice a week.

Senator HARKIN. Twice a week?

Ms. Turner. Yes. I go tonight.

This is Harvester Baptist Church, where I go to church every Sunday.

This is Kentucky Fried Chicken.

Senator HARKIN. Now, wait a minute. Is that your favorite eating place?

Ms. Turner. I used to work there.

Senator HARKIN. Oh, I see. How long ago did you work there?

Ms. Turner. It's been about a week—no, a couple weeks. I work somewhere else now, K.T. Tools.

This is me at Ocean City, in a hot tub.

That's all.

Senator HARKIN. That's very good.

Ms. WEISENMILLER. In many States, the developmental disabilities components, including University-Affiliated Programs, developmental disabilities councils, and protection and advocacy, make possible the demonstration of new approaches to critical issues like community living and have demonstrated the capabilities and competencies of individuals with developmental disabilities.

[The prepared statement of Ms. Weisenmiller and Ms. Turner follows:]

#### JOINT PREPARED STATEMENT OF NANCY WEISENMILLER AND DEBRA TURNER

Nancy Weisenmiller: Debra Turner and I want to thank you for the opportunity to speak to the Subcommittee on Disability Policy. From the age of 14, until the age of 33, Debra lived in an institution for people with mental illness. In the institution, Debra lived in locked buildings, had no decision-making power, and no opportunity to make choices. Four years ago, Debra was discharged from the institution, and today she lives in a townhouse, is taking G.E.D. courses, and attends church every Sunday (one of her favorite things to do). Debra voted for the first time in the last presidential election.

Debra is a member of the legal class (the Knott's class) represented by the Maryland Disability Law Center (the Protection and Advocacy program in Maryland). The Kennedy Krieger Institute, Maryland's university affiliated program, is providing the supports and services that Debra needs to live independently.

In many States, the Developmental Disabilities Councils, the protection and advocacy programs and the university affiliated programs are working to demonstrate new approaches. These programs have shown that by focusing on the capabilities, competencies and preferences of people with developmental disabilities, they can achieve independence, productivity and full inclusion into the community.

Debra Turner: I want to tell you about my experiences in moving from the institution to the community. I want to show a few slides that represent important parts of my life and the changes in my life since my discharge from the institution almost four years ago. The slides are:

1. Picture of Spring Grove
2. Me before moving from the institution
3. Home
4. Dusting my Elephant Collection
5. Studying at my desk for my G.E.D.
6. Harvester Baptist Church
7. Job at Kentucky Fried Chicken
8. Vacation

My life today is very different from what it was just 4 years ago. I am proud of what I have accomplished. Nancy, my roommate, is a good friend and has been very important to me. My other friends are also important. I feel that with continued opportunities and support, I can accomplish even more.

Senator HARKIN. Nancy, Debra, thank you very much for being here.

I wanted to recognize someone in the audience who has testified here before. Marietta Lane, it is good to see you again. We're glad you are here.

Again, I appreciate your testimony, and I don't say that gratuitously, because I think what you have said here today helps us understand a little bit better about what is important and what is possible.

Mr. Graber, you are right—we do pass bills, whether it is ADA, or the Developmental Disabilities Technology Act, covering a lot of people. But again, the end result, as I said earlier to someone, is that person getting that assistive technology device. That's what we are after, and how do we set up the system to do that.

Your whole emphasis on thinking about that one individual is true. That is really the end result which we are after: to set up a system of some form that is adaptable and changeable with time, that lets that individual know that he isn't just hanging out there all by himself or herself, that there is a community effort, and that the old ways of doing things, like with Debra—warehousing these individuals, putting them in an institution and forgetting about them—we are going to change those things.

I just wanted to reassure you that while we are doing it in the broader context, the end result of what we are looking at is Debra and Charlie and other people. They are the end result.

Mr. Graber. If I could comment on that, I think what Ms. Turner is doing is excellent. And where she's at now is not a result of her deep and complete understanding of her disability—it has nothing to do with that. It has to do with her discovery of her capabilities. She moved the walls of her disability. That's called growth. Real people are allowed to do that. And we are all real people, and we need a shot at it.

And you mentioned about the dream thing. Dreams are realities that have not solidified yet, that's all. And by working with a person's capability, you prepare them for opportunity. When they can act on their opportunity, they can realize their dreams, and this young lady is proving that right now.

Senator HARKIN. Absolutely.

Debra, just picking up on what Mr. Graber said, what is the best thing that has happened to you since you moved out of the institution? What do you like the most?

Ms. Turner. Going out for lunch or breakfast or supper.

Senator HARKIN. Just being able to go out for lunch or breakfast on your own.

Ms. Turner. Yes.

Senator HARKIN. There, you have it. A young woman testified back when we were passing the Americans with Disabilities Act. She was severely disabled, and everyone was talking about all these esoteric things about the ADA bill and what it was going to do, and she said all she wanted to do was just go out and buy a pair of shoes like anyone else—just go to a shoe store and buy a pair of shoes. So it gets down to those kinds of things, doesn't it? Just going out and eating—something that a lot of us just take for granted, I think.

Ms. Swenson, I want to know more about Charlie and what he is thinking about, what he is looking ahead to. Charlie is 11.

Ms. SWENSON. He will be 11 in August.

Senator HARKIN. Well, I have a daughter who is 11, and they don't look ahead to much except what they're doing tomorrow.

Ms. SWENSON. Yes. He's looking ahead to turning 11.

Senator HARKIN. That's true, so I shouldn't put any extra burden on him. I understand that. But is he looking forward to tomorrow?

Ms. SWENSON. Yes. Charlie's life has changed dramatically since he has been included with other children in school. The first thing that happened is socially. Charlie has a lot of autistic behaviors, and the first thing that happened was that he stopped yelling all the time. When he was in the segregated room, he would just make noise all day long. Now that he is included, you can't really tell him from the rest of the kids. The rest of the kids yell a little bit, too.

But the first year he was included, his teachers—his collaborative team—there is a paraprofessional, a special educator, and his regular 4th grade teacher—got together and started using facilitated communication with Charlie, which is an assistive technology, but it is not a device. It is a way of offering human support to people to help them focus when they are spelling.

And what we found out was that Charlie can read. This year he is doing math at grade level—well, he is doing math at a 4½ grade level, and he is in 5th grade. He answers questions. Charlie, we think, must have always been able to do a lot of this stuff; we just didn't have any access to it.

I have always told my boys that when they go to college, that living in a frat house would be the only group home I would ever let them live in. And Charlie will mention that every now and then. I don't know if he is really thinking about going to college.

Senator HARKIN. How about the people around you; have you noticed a change in people's thinking?

Ms. SWENSON. Enormous change. I really meant what I said coming home that day, that it was going to be easier to change the world, because there are a lot of good people out there, and if you just go to them—I didn't know anything about disabilities before I had Charlie—if you go to people and say, look, here's the deal, here

is why it is important for Charlie and people like Charlie to be included; we need to have inclusion, we need to have people understanding these things. Charlie needs help more than he needs anything. He needs friends around him who are able to participate and help him participate. Once you explain those things to people, I don't think there is any end to it.

I told you Charlie went from a segregated classroom in a segregated school to inclusion in a regular classroom. Well, he started with 5 minutes of inclusion the first year. Five minutes was all I could get the teachers to agree to—story time after lunch. And after a week, the rest of the kids in the class wouldn't let him go back to the special room. The kids said, "No. He wants to stay here."

Then, the next year, he was included in a 4th grade full-time, and that year, the principal decided to close the special education classroom, so all of the kids in the school were included. It has become the most popular elementary school in Minneapolis because of that sense of belonging that has been created kind of around the kids with disabilities.

Senator HARKIN. What is the name of the school?

Ms. SWENSON. Fulton School, 700 kids. And this year, our principal—who was brand new to inclusion when he started in the fall—has started to call citywide—he put out an invitation to all of the schools in Minneapolis, and we had 120 people at our first meeting, parents of regular ed kids, parents of special ed kids, teachers, principals. They wanted to learn about inclusion.

Now there are 43,000 students who go to school in Minneapolis, and 5,000 of them have IEPs. So, does change happen? Yes, it happens.

Senator HARKIN. I visited a school in Minneapolis one time that had taken great strides to integrate kids with disabilities. I am just wondering if that was Fulton.

Ms. SWENSON. It wasn't Fulton. We didn't even have an elevator until 2 years ago.

Senator HARKIN. All right, all right. It wasn't Fulton.

Ms. SWENSON. But there are kind of waves that go out, and it is cool to watch. A lot of stuff is happening in the school now that I didn't even know about. So people are accepting these values as their own, and they are making them move.

Senator HARKIN. Good.

Senator Durenberger.

Senator DURENBERGER. I've got one question, and maybe I can ask it of everybody. I lived halfway between Fulton and Burroughs, so my kids went to Burroughs. I was PTA president at Burroughs, which is what qualified me to get elected to the Senate.

Ms. SWENSON. Yes—I've had my eye on the school board.

Senator HARKIN. It's a good training ground. [Laughter.]

Senator DURENBERGER. I was thinking about two things when you were talking. One is Diane Ravitch's piece yesterday in the Washington Post about evaluating schools, not just evaluating teachers and things like that. There are some unique public schools in this country, but they are really hard to find, because it is so hard to sort of break the molds, get off the paper work, tear down the walls, and do things differently if somebody is going to be there

to criticize you. And it is always some parent or somebody within the institution that doesn't understand or doesn't like the way the institution is being responsive to the inclusion or whatever you call it.

The other thing I thought about is that when you have a unique educational institution that is actually thinking about education in a much wider context and a much more inclusive context, and allows the kind of flexibility that all the kids would like to see in the program, and the word gets out, everybody wants to go there. But of course, the system won't permit that to happen. There are only so many who can go there, and everybody else ends up having to go to the private schools—rather than have all the other public schools in the system sort of look at this one and ask what are they doing that everybody wants to be part of. And the response is, sorry, we're only doing them, or we got a Federal grant, or something happened that allowed us to do that. So that's a frustration.

The other thing, though, that I always concern myself about is why are we doing this here, and why do the two of us sit here. I know why I'm here. It is because Tom Harkin is here. Tom is so sensitive to these things, and he is always creating new and better ways to do things. But by the time what goes through Tom's head and through this bill actually gets down to the Fulton schools and the Charlies and the Joshuas and all the rest of these people, it's hard to know whether we have had any impact at all.

So this sort of building from the bottom up, starting sort of one-on-one, and developing from that ways in which we can meet needs has an awful lot more appeal. But it always runs into resource issues, and when you have a resource issue, then you have accountability, and if we're going to spend Federal tax dollars, then we've got to make those people account for it; if they do it at the State level, then they've got to account for it. And usually the accounting is on the basis of inputs and the size of the room and the number of kids in the class and so on, rather than outcomes, the result.

I mean, I sat here as all of you did, spellbound by what Lee was saying about these relationships. Well, there is nothing in accountability in America today that permits that to happen, except inside him, what motivates him to be a teacher or whatever he may be. But the system doesn't permit the rewards, if you will, for results, for outcome.

I always end up asking the question can we not find some way to judge outcomes, to judge results, and then ask how did you get there, and maybe by that sort of spread it around, so more people get the idea, and then the system of accountability might change as well.

Lee, do you have any thoughts on that subject, or anybody else?

Ms. WEISENMILLER. I think that from the level of adults and generally the people that I work for are people moving out of institutions into apartments, it has totally changed in 4 years, from not wanting to rent to someone to saying, "We have this person we want to move in," and the landlord actually saying, "Fine. Do we need to make any modifications? Do we need to put ramps in? Do we need to put shower bars? Do we need to have special locks on the doors, or special handles on the doors?" And that is a real difference, and that is a real positive change that I have just seen.

That has been mostly within the last year. But I see that the community is more accepting of individuals moving into the community.

Recently, we moved four houses down the street because we had a cat and wanted to keep the cat, and we couldn't where we were living. So in the process of moving, we had all these neighbors that we didn't really know when we were there who were saying, "We're sorry to see you leave." So the community has been accepting. And I think it is, if for nothing else, just the fact that legislation and all these acts come out, and they are in the newspaper, and people read about it, and they are more aware of things, and they are looking at what is happening and being more open-minded about it. I have seen large change in that area.

Senator HARKIN. Lee.

Mr. Graber. Some things you have to believe to see. Albert Einstein said that. Keep it simple. The problem is that when it leaves here, it is tight, it is solid, it has a good value base. When it gets out there, it becomes real complicated. Everybody thinks they have to break it up into all of these various components, and we end up with a chain of command rather than a flow of responsibility. And chains rust. They rust in little cubicles someplace, in somebody's office. Flow of responsibility flows around what the need is, and that need is based on the capability of the individual—relentlessly, constantly, what can that person do, not matter how great it is or small it is, and developing it.

It takes three simple things to make you happy—somebody to love, somebody to love you, something to look forward to and something meaningful to do with your life. Somewhere in that configuration there is happiness for us.

I cannot guarantee that my son and my daughter are going to find those three things. I can't guarantee that. But I can definitely guarantee they are going to have the opportunity to look for them. That's what education does—preparing for the opportunity. And they will have the opportunity to look for them simply because we can assure that what we do here can be translated simply out there. And it is one at a time, and you focus on needs, and the needs are based on capability. That's it.

Ms. SWENSON. And you have to ask people. You have to let each person say did this work. We sometimes forget that people with disabilities can judge whether something worked for them, or that mothers of kids with disabilities can say, yes, this is a good program—here's what I would change, here is what I would like.

In schools, it actually is easier to change a school, because teachers have a lot of flexibility, and they also are very responsible and outcome-driven, typically. If they are doing something that is not working, they will have a whole bunch of angry parents coming in, and they don't want that.

Mr. Graber. That is really excellent, it really is. If you make a mistake, it's a learning experience. If my kid makes a mistake, it's a behavior problem. Now, if it isn't a behavior problem, it is directly attributed to his deficiency and defectiveness. So you are constantly defining and redefining what is wrong with my kid, because he has got to have a label. But we'll suffer the labels—just see that we get the money.



Ms. SWENSON. But human services systems are less flexible—people who deliver services to people, whether it is intended to support you in your home or not, do not have the flexibility often to deliver what you need. It is a terrible problem. And nobody ever asks: Does this work?

Charlie is rated for 56 hours of personal care attendant service per week. Now, I can't have somebody in my house 56 hours a week. What I really need is an elevator. An elevator would cost the same as 1 year's worth of personal care attendant services, but they can't give me an elevator. There is no flexibility. Therefore, they can't ask me "What do you need? What's the outcome?" The outcome is I want Charlie on the second floor, regularly, during the day—but I don't really need staff to do that.

Senator DURENBERGER. Thank you.

Senator HARKIN. Thank you all very much.

I just want to correct one thing that Senator Durenberger said. I'm not in the habit of correcting him, but I will correct him. He was very kind in his comments about me, but I want you all to know that Dave Durenberger is not here because Tom Harkin is here. Dave Durenberger was here before I ever got into this, and he has been a strong supporter of what I call "people programs," improving the quality of life for people all over this country, long before I was ever here, and I am just proud to be associated with him in the endeavor. And I mean that. So you should be very proud of him.

Ms. SWENSON. Oh, I am.

Senator HARKIN. Good.

Thank you all very much. That was a good panel. Andy said you'd be a good panel, and she was right.

Senator HARKIN. We'll move now to our last panel.

We welcome Steve Eidelman, executive director of the Joseph P. Kennedy, Jr., Foundation, testifying on behalf of the Consortium for Citizens with Disabilities; John T. Porter, chair of the Illinois Council on Developmental Disabilities, testifying on behalf of the National Association of Developmental Disabilities Councils; Sara Wiggins-Mitchell, director of the Division of Advocacy for the Developmentally Disabled, New Jersey Department of Public Advocate, Trenton, NJ, testifying on behalf of the National Association of Protection and Advocacy Systems; and Ann Rhodes, vice president for university relations, University of Iowa, Iowa City, IA, testifying on behalf of the American Association of University-Affiliated Programs, accompanied by Al Healy, director of the Iowa University-Affiliated Program.

Again, we welcome you today and thank you for coming and for all of your work. Again, your statements will be made part of the record, and if you could summarize, I would appreciate it.

We'll start with Steve Eidelman. Steve served on the CCD Task Force on the Developmental Disabilities Act. In his former role as State mental retardation program director in Pennsylvania, he has had extensive interaction with the programs under the DD Act.

Steve, please proceed.

**STATEMENTS OF STEVE EIDELMAN, EXECUTIVE DIRECTOR, JOSEPH P. KENNEDY, JR., FOUNDATION, WASHINGTON, DC, ON BEHALF OF THE CONSORTIUM FOR CITIZENS WITH DISABILITIES; JOHN PORTER, CHAIR, ILLINOIS COUNCIL ON DEVELOPMENTAL DISABILITIES, WOOD DALE, IL, ON BEHALF OF THE NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES COUNCILS; SARA WIGGINS-MITCHELL, DIRECTOR, DIVISION OF ADVOCACY FOR THE DEVELOPMENTALLY DISABLED, NEW JERSEY DEPARTMENT OF PUBLIC ADVOCATE, TRENTON, NJ, ON BEHALF OF THE NATIONAL ASSOCIATION OF PROTECTION AND ADVOCACY SYSTEMS; AND ANN RHODES, VICE PRESIDENT FOR UNIVERSITY RELATIONS, UNIVERSITY OF IOWA, IOWA CITY, IA, ACCOMPANIED BY DR. AL HEALY, DIRECTOR, IOWA UNIVERSITY AFFILIATED PROGRAM, UNIVERSITY OF IOWA, ON BEHALF OF THE AMERICAN ASSOCIATION OF UNIVERSITY AFFILIATED PROGRAMS**

Mr. EIDELMAN. Thank you, Mr. Chairman, Senator Durenberger. I am here on behalf of the CCD, and I have had a long and colorful history with the Developmental Disabilities Act. I was a trainee in a University Affiliated Program and staff member there; I ran a community developmental disabilities agency and received DD grants; I worked extensively and consulted with Developmental Disabilities Councils and have been sued six times in my official capacity by protection and advocacy agencies, five of which times they won—but they were right.

CCD's recommendations are somewhat more formal than the previous panel. However, we think we have some very important things to say about the Act. The Act has caused dramatic change in the past 20 years in the way people with disabilities and their families experience life in their communities. We particularly like that the Act has moved to more user-friendly language, and while that may seem only out of political correctness, when the Act gets translated down to State and local governments and to agencies dealing with people with severe disabilities, that language is very important.

There are four parts about the councils I'd just like to touch on briefly. One is autonomy. Speaking as a person who has worked with State government, it is very important that the councils be allowed to fulfill their mission. State government has a tendency sometimes, when councils are out on that cutting edge, to try to rein them back. So the autonomy of councils from that kind of governmental oversight in terms of their policy and day-to-day operations is very important, recognizing that they are part of State government.

Second is the reappointment of council members. There is nothing less functional than a council with only 70 or 80 percent of its members, and the process in the three States where I have worked has been highly variable, so we are glad that's in the new version.

Linkages to other councils is extremely important, especially those to Part H and people working around vocational rehabilitation, to tie those programs together so that where they overlap and interrelate, they can learn from each other and build on each other's strength and knowledge is crucial.

Relative to protection and advocacy systems—and I know Mr. Decker is quite nervous that I am here speaking about P and As—but consumer and family involvement on P and A governing boards is crucial. I have seen again in three different States where P and A boards have become a very focused entity and almost group thing, and I think to keep people focused on what the real issues are, you need people with disabilities on those boards, and you need their families who have experienced the service system to help them both set priorities and to communicate to the field what is important and what is possible.

The biggest point in the P and A section of the bill is the language clarifying access to private facilities. We are at an interesting point in this country where the number of people in large private facilities in many States actually exceeds the number of people in public facilities in those same States; and the primary difference between many of the large public facilities and the large private facilities is the quality of the furniture, not the quality of life, and it is very important that the P and As have access. I have seen them have difficulty again in three States getting into private facilities. I think your language moves a long way in that direction.

Finally, I think the university-affiliated programs are at an exciting juncture. With health care reform coming down the pike, the need for training primary care practitioners, not only specialists, but generalists, about developmental disabilities is more important than ever before. As more and more people are living successfully in communities, the movement that created the Developmental Disabilities Act in the early seventies sort of divorced itself from physicians and health care professionals because of the roles they were in supervising institutions at that time. It is now time to come back together. We desperately need well-trained clinical professionals in primary care medicine and dentistry, as well as the allied health fields, and the university-affiliated programs are in a very good position to do that for adult practitioners. I think they have pretty much done it for children in most parts of the country.

The Projects of National Significance offer us an opportunity to especially enhance our collection of data over time, and one of the things that I have noticed since coming to Washington when we have policy discussions is the paucity of good data that lets us describe what people are experiencing in their communities and in the States, and we particularly like the language there.

I'd be glad to answer any questions later.

[The prepared statement of Mr. Eidelman follows:]

#### PREPARED STATEMENT OF STEVE EIDELMAN

Good morning Mr. Chairman and members of the subcommittee. My name is Steve Eidelman and I am the Executive Director of the Joseph P. Kennedy Foundation. I am here today representing the Consortium for Citizens with Disabilities (CCD), a working coalition of more than 100 national organizations which has advocated on behalf of people with disabilities since 1971. The CCD does its work through task forces, thus today I am representing the CCO Task Force on Developmental Disabilities, of which I am a member.

CCD has made its recommendations on the reauthorization of the Developmental Disabilities Act, which accompany my written testimony for the record. My oral testimony will summarize that document. Twenty-one organizations with members across the country have contributed to the development of the CCD recommendations.

In the early 1970's, Congress saw that people with developmental disabilities were being excluded from the few services that were available to individuals with disabilities and were specially vulnerable to abuse and neglect. Since 1970, the Developmental Disabilities Act has helped lead the field away from an institutional mind-set to a belief in that individuals with developmental disabilities must have the opportunity to live, work and play in their own communities and that states must have the capacity to support and foster these opportunities.

Moreover, with the passage of the landmark Americans with Disabilities Act, we, as a Nation, affirm the rights of all Americans to live independent, productive lives. The draft DD Act reauthorization builds on these principles of inclusion and self-determination.

In reauthorizing the Developmental Disabilities Act, Congress has designed a four-part strategy for addressing the needs of individuals with developmental disabilities. These four programs have distinct and complementary purposes:

The Basic State Grant funds DD Councils to do systemic planning, demonstrate innovative approaches, educate policy makers and advocate within State government.

Protection and Advocacy Systems, the legal arm of the DD Act, protect the rights of individuals with developmental disabilities.

University Affiliated Programs provide training, technical assistance, and disseminate information to improve States' capacity to meet the needs of individuals with developmental disabilities and their families.

Projects of National Significance, the national research and development resource, fund cutting edge research and disseminates best practices nationwide.

CCD recommendations center around four themes:

Simplify the language to be "user friendly" and provide clear structure for each program;

Strengthen the effectiveness and interdependence of the four programs and increase the autonomy of their policies from state government and strengthen their accountability to the public;

Enhance linkages to other related programs which serve individuals with developmental disabilities and their families; and

Strengthen the programs' responsiveness to the changing needs of individuals with developmental disabilities and their families and look toward the future.

#### PART A—GENERAL PROVISIONS

The Developmental Disabilities Act has always led the way in disability policy in defining state-of-the-art services and supports, and cutting edge concepts, and in using appropriate language when referring to people with developmental disabilities. The Senate proposal includes "people first" language and tries to employ easily understandable terms throughout the bill. Because the DD Act is so often used as a teaching vehicle for disability policy, the Senate proposal greatly improves current law.

#### PART B—FEDERAL ASSISTANCE TO STATE DEVELOPMENTAL DISABILITIES PLANNING COUNCILS

There are four major areas related to DD Councils I'd like to mention. First, the Senate draft bill strengthens the autonomy of the Councils by requiring an assurance that the State does not interfere with the systems advocacy or other mandated activities of Councils. While DD Councils are "within State government" they are advocates within State government and, as such, should never have their policies or program directions be controlled by any agency or office of the State. CCD supports this approach.

Second, the Senate draft bill contains provisions to ensure that Council member nominations are made in a timely manner to avoid long-term vacancies which thwart the effectiveness of Councils. The bill also requires that State agency members of the Council have sufficient authority to speak for the agencies. In addition, the bill establishes a nominating process to assist the Governor in making appropriate appointments to the Council. CCD endorses these efforts to ensure that Council membership is able to implement congressional mandates.

Third, several new provision in the draft bill enhance DD Council linkages to other federally-assisted Councils and programs, such as the Independent Living Councils, the Interagency Coordinating Council for early intervention, the Parent Training and Information Centers and the Mental Health Councils. CCD feel that these linkages will increase the effectiveness of state-wide planning across agencies as well as across disabilities.

Fourth, while the draft bill makes only minor changes in the substance of the State Plan provisions, it has reorganized them considerably. This is a great improvement and gives the State Plan section a logical flow from Council policy research, planning, and plan development to implementation, monitoring and evaluation activities.

#### PART C—PROTECTION AND ADVOCACY SYSTEMS

Mr. Chairman, I would like to turn now to the section of the Act concerning Protection and Advocacy, Part C. While the representative of the Protection and Advocacy Agencies will be testifying later, I'd like to spend a few minutes discussing some broad points CCD would like to make.

A critical component in the draft bill is the increase of consumer involvement. The language in the draft bill broadens the make-up of the P&A Governing Board to include individuals with disabilities who are eligible for services under the Act. It would also include parents, guardians, advocates, or others authorized to represent individuals who have received or are currently receiving services from the P&A. In states where there is no Governing board, the new language will establish an Advisory Council which shall be composed of a majority of individuals who are eligible for services. This Advisory Council will advise the system of the policies and priorities established by the P&A to carry out its mandate to protect and advocate for individuals with developmental disabilities. Additionally, the new language mandates that public notice be made to announce any Federal programmatic or administrative review of the P&A. Public comments will be included in the on-site visit report. These additions will greatly enhance consumer input into the operation and direction of the Protection and Advocacy System in each state.

Another important part of this draft bill is that it moves in the direction of strengthening the authority of the Protection and Advocacy agencies. In order to effectively represent people with disabilities, the P&A must have the ability to have access to those individuals residing in public and private facilities. The P&As spend too much of their resources re-fighting battles in court to establish their standing to represent people with disabilities. This draft language adequately addresses this issue by giving the P&A authority to investigate reports of abuse and neglect in DD facilities at reasonable times and locations and authority to pursue remedies in the system's name when a resident of a facility fears retaliation.

The new language also gives the P&A greater security with regard to its limited resources. Several P&As are housed within state agencies, bringing them under State regulations concerning expenditure of funds. Because of the current fiscal trouble in which states find themselves, several state-agency P&As have found restrictions placed on their use of the funds authorized and appropriated by Congress. There is a provision in the draft that prohibits a state from placing hiring and travel restrictions on the P&A if those expenditures are necessary in the P&As efforts to carry out its mandate. Similar provisions are also applied to Councils.

Lastly, the most critical issue for people with developmental disabilities is the lack of adequate resources available to fulfill the P&A mandate. CCD is concerned that the P&As have had to prioritize cases, establish waiting lists and turn away eligible people who have experienced very serious rights violations. The reauthorization should serve as a vehicle not only to strengthen the program but to remind Congress of the need to adequately fund this small but crucial program.

#### STATE ALLOTMENT ISSUES

CCD has recommended that the DD Act amendments address a problem with the formula currently used to determine the amount of individual state allotments for the State DD Councils and the Protection and Advocacy Agencies. For some reason, when the formula is applied, even when appropriations increase, many state allotments are reduced in what appears to be a far greater percentage than changes in their population or per capital income would suggest.

In Fiscal Year 1993, when there was a one percent reduction in the Basic State Grant appropriation, more than 30 states experienced a reduction, some by as much as four percent. The proposal under development by the Subcommittee to solve this problem is a step in the right direction. CCD will continue to work with the members of the subcommittee to find a equitable resolution for this matter in this reauthorization.

#### PART D—UNIVERSITY AFFILIATED PROGRAMS

The proposed reauthorization includes a significant update of the definition of UAPs. Specifically, this new definition supports the current activities of UAPs which

include the interdisciplinary preservice preparation of students and fellows, community service activities which include community training and technical assistance and may also include state-of-the-art direct services to individuals with developmental disabilities and their families. Finally, UAPs must disseminate information and research findings.

In order for individuals with developmental disabilities of all ages to have a greater opportunity to live independently in their own communities, they must have access to appropriately trained primary health and support personnel. Unfortunately, there continue to be critical shortages of well trained professionals, including occupational therapists, physical therapists, nutritionists, doctors and nurses. Furthermore, quality trained personnel in the areas of individual support, family support, Community-based living, assistive technology and consumer empowerment are urgently needed. A principle means by which UAPs respond to these needs is by preparing personnel for careers in the field of developmental disabilities.

In addition, 38 UAPs operate specialized training initiatives in one of the following areas: early intervention, aging, community services, positive behavior supports, assistive technology services. I am particularly pleased that the reauthorization adds the Americans with Disabilities Act to the topic areas for training projects. These training projects are invaluable to ensuring the availability of quality trained personnel necessary to support individuals with developmental disabilities in their own communities.

In addition, UAPs provide support to individuals with developmental disabilities in their communities through the provision of technical assistance and community training. For many UAPs, it is the technical assistance activities, as opposed to the provision of direct services, that has had the greatest impact on ensuring that state and local service delivery systems can adequately respond to the needs of individuals with disabilities.

The reauthorization also continues several long term priorities of CCD with respect to the UAPs. First, the draft recommends a program in every state. There currently are 57 UAPs in 49 states and 2 territories. Only Wyoming and Virgin Islands remain unserved. Next, the draft recommends awarding a training project at every eligible UAP. The third priority in the bill is to increase the training project from \$90,000 to \$100,000. The final priority in the bill is to increase the UAP core award from \$200,000 to \$250,000.

CCD is also supportive of the Senate draft's proposal to remove the recovery authority. All UAPs that were constructed with federal dollars are now 20 years old. Therefore the recovery authority is no longer necessary.

#### PART E—PROJECTS OF NATIONAL SIGNIFICANCE

CCD agrees that current priorities under the Projects of National Significance should be retained. In particular, CCD strongly supports the ongoing data collection activities funded by the Projects of National Significance. The new initiatives which address the relationship of the developmental disabilities community to the Larger disability community are a significant and needed addition.

There are three million individuals with developmental disabilities in the United States. There are forty three million Americans with disabilities. Many individuals with disabilities are interested in being included in the DD programs. To begin to address this matter, the CCD has recommended and the Senate discussion draft reflects, that the law looks at whether the needs of people with disabilities other than developmental disabilities can be appropriately addressed by the DD programs.

We believe the research and pilot test approach contained in the draft bill is prudent, while beginning to respond to people with disabilities of later onset and of less severity than those with developmental disabilities.

Under the Projects of National Significance, COD proposes research on the State DD Council programs that have already expanded their focus and what actions are necessary to achieve program expansion. CCD strongly urges that Congress provide tie additional resources needed to complete those activities before the next reauthorization.

Finally, authorization of appropriations. The four DD programs have experienced real losses in dollars during the last decade. We urge the members of the subcommittee and the full committee to raise the authorization level's for the four programs to redress these losses.

Senator Durenberger [presiding]. Maybe I could ask you a question, Steve, because I don't know how long I'm going to be able to stay—and I apologize to everybody. I have been in and out in two different things, which the chairman can't do; I mean, he just

makes up his mind ahead of time he can't do all those things—but he is responsible. Minority members are less responsible, so we try to do three things at the same time.

But before I turn to John, Steve, help me understand a little bit about—it is a question I asked earlier, and you may not have been here—we were talking about health insurance and health reform. One of the things that has been missing in all of this debate is a much broader view of health care. Everybody is talking about buying insurance policies for 257 million Americans. That is not the biggest health problem we face in this country. A lot of the things we are talking about here, or the 24 murders we've had in this town in the last 4 or 5 days, or—you know, there is a breadth of health care that doesn't seem to be encompassed in health care reform. Anyway, as we are talking about doing things differently and better in our society, where does the financial commitment to access to medical care services, and then the broader set of services that is often described as long-term care or care for the chronically ill, or whatever some of these names are that we have, but they are part education, they are part housing, they are part social services, they are part quality of life, they are part the sort of spiritual feeling I got listening to Lee speak a little while ago. But it is where you need the help of a professional. How, as we approach this issue of reforming the system and changing the role of the national government and the private insurance system, and getting the caregivers to give us the kind of care that is most appropriate to the individual, where do some of these things fit in?

Mr. EIDELMAN. That's a tough question. We have been struggling with that. I think there are two distinct answers, Senator. Relative to acute and primary health care, the three programs funded under this Act need to work with the health alliances that are created to make sure people with severe disabilities have access to care, have access to the professionals needed to do the care, and are actively included in getting good care, not just eligible, because I am afraid people are liable to become eligible for care without actually getting the appropriate care.

Long-term care and personal care, I think, is a much more difficult struggle. It has been part of health care only because of our utilization of Title 19, and I think conceptually we need to separate it from acute and primary health care, and we have to talk about supporting people where they choose to live and building a system, as the gentleman said earlier, one person at a time, and talking about all those things as separate from the health care delivery system.

I am not convinced, having worked in hospitals and in a medical school, that you are ever going to be able to integrate those two. I am not sure they need to be integrated. People who receive long-term care need services and supports from the primary and acute health care system, but it needs to be driven by their personal desires and needs, and not by medical practice, dental practice, nursing practice.

Senator DURENBERGER. Or reimbursement systems, or even categorical approaches to solve problems.

Senator Eidelman. That's correct, yes. And I heard the woman talk earlier about not being able to get an elevator. The reason she

can't get an elevator is an obscure provision in Title 19 about capital expenditures under either Medicaid waivers, if that's how that particular service is funded, or supportive living arrangements. And it is not because it doesn't make sense financially or outcome for her family. It is because Title 19 was written to reimburse hospitals and nursing homes.

Senator DURENBERGER. Thank you.

Senator HARKIN. John Porter, chair of the Illinois Planning Council on Developmental Disabilities. John has been chair of the DD Council for 5 years and is on the board of directors for the NADDC, representing the Council chairs.

Welcome, John. Please proceed.

Mr. PORTER. Thank you very much, Senator.

My name is John Porter, and I am chair of the Illinois Planning Council. I am also the father of John, Jr., who is developmentally disabled and who, when he found out I was coming, said to make sure he told you hello and that he loves living in a community.

Senator HARKIN. Great.

Mr. PORTER. I am also a 100 percent disabled veteran myself, so I have been involved in disabled issues for a number of years.

I'd like to thank the subcommittee first of all for the fine work you have done in this Act. It is great to see some of the changes that are going to be taking place.

Specifically on council autonomy, I think Steve stole some of my thunder because he mentioned some of the things I am going to say. But one of the important pieces of that is council autonomy. The Illinois Planning Council became independent in 1990, after a lot of work and effort, and as a result, we now have more control over our staff, and we can advocate for inclusion in State programs, which we had difficult doing before.

While independence is not feasible for every council, a number of them do want to make that change, because at our last national meeting, the council chairs, almost all of them, said that they wanted to talk about independence and becoming independent in the future. So that's a major issue with them, but I do recognize that each State is different, and with the language that is in there, even if they can't become independent, at least it is going to be easier now to get away from some of that influence and control by the State.

In terms of flexibility and empowerment activities, the council program gives us a lot of flexibility in terms of innovation and allows us to do some things and to let people with disabilities make decisions for themselves. And as a long-time member of the civil rights movement, I found out a long time ago that people with a problem are the best ones to tell you what they need to solve the problem. So we have tried to do our best to empower people with disabilities to make decisions for themselves as well as family members.

I have heard a number of comments about the "People First" language, and I can't say enough about that. We are strong supporters of the "People First" movement. In fact, we have a "People First" member on our council, and the first thing she did was to make us change our format of our materials so that it was legible for her, which also made it easier for us.



We have a large investment in empowerment, and have spent a lot of time making changes and doing things in terms of self-advocacy. As I said before, we support "People First." We are very involved in family support legislation. In fact, last November, we invited 17 families in from around the country, and they prepared national family support legislation, or at least a policy on national family support.

We are one of the few councils who are able to have people with cognitive disabilities on our councils. We have at least four people who are primary consumers with cognitive disabilities, and one of our people is now a voting member at the national level here at the NADDC, and she also represented America at the "People First" conference in Toronto this past week. There are 117 countries, and she was selected to carry the American flag in Toronto. I was there at that conference, and it was just a wonderful thing to see.

At least half of our members, of course, are people with disabilities and their family members. I think we have done a very good job of bringing people with cognitive disabilities onto our council.

We work very hard in getting people with disabilities on State boards and commissions because we think they need to be represented at all levels. So we have worked very hard to make sure that is accomplished.

In terms of council accountability, Steve mentioned about the vacancies. One of the pet peeves with almost every council is the sluggishness with which we get appointments, and our council is no exception. We are fortunate because our members continue to serve until they are reappointed. In some States, that is not the case, and what happens if you do not have reappointments is that you can't get council business done, and more importantly and particularly, if the members that are rotated off or no longer there are people with disabilities, that means this is a segment that is not even being represented. So it is a problem, and I am glad to see you have addressed it in allowing us to report that to HHS if there are significant delays.

Conflict of interest—we have long had a conflict of interest policy, because once you have that, it makes it very easy to know what you can and you cannot do. A lot of councils don't have that, and I am glad to see that in the Act, because we do need that.

In terms of the council, systems change—all of us to a certain degree work with all disabilities. It is my personal belief that, although we are working with people with developmental disabilities, whatever you do for people with DD, other people with disabilities benefit. If we work with people in transportation, that benefits everybody.

We have a program in Illinois where we work with community colleges, getting people with DD in the enrollment process. If help people with DD, other people with disabilities can also get into that process. So I think that all people with disabilities whatever we do with DD.

Now, whether or not to change from a developmental disabilities program to a disabilities program is a very complex matter, and I'm not sure I have all the answers to that, but it needs to be remembered that the DD population is special. Out of 43 million people with disabilities, there are only 3 million with DD. The reason

for the Developmental Act formation in 1970 was to serve those people, and I think they are neglected, they are underserved, and we need to continue our focus on that.

As to the Projects of National Significance, I think we continue to need the research that the UAPs and the other groups do, because without the research, we do not know how to address our issues in the future. We have a lot of work to do, and some of those longitudinal studies and data that we get help us do what we need to do.

A last word on resources. We have a very small program. It is the only program I know of where the Federal Government spends money just on DD. The needs have grown tremendously, and our resources have declined. So I fully support the CCD's recommendation for \$77.4 million for the program.

With that, I'd like to thank you very much for listening to me, and if you have any questions, I'll be glad to answer them.

[The prepared statement of Mr. Porter follows.]

#### PREPARED STATEMENT OF JOHN PORTER

Good morning. My name is John Porter. I'm the Chairman of the Illinois Planning Council on Developmental Disabilities and a member of the Board of Directors of the National Association of DD Councils, chosen by Council chairpersons to represent them nationally. I've been a member of my Council for eight years, the last five of as chairman. I have a twenty-four year old son who has developmental disabilities; he lives in the community with a house-mate and a staff member.

I'd like to thank subcommittee members and staff for the fine work you have done in developing proposed amendments to the DD Act. If adopted, they will solve several key problems Councils have and considerably strengthen the ability of Councils to be independent systems advocates.

My testimony will focus mainly on Part B of the Developmental Disabilities Act, the Basic State Grant Program, operated by Developmental Disabilities (DD) Councils, and will address five areas: DD Council autonomy; DD Council flexibility and empowerment activities; DD Council accountability; DD Council Systems Change Activities Beyond Developmental Disabilities; and Resources Issues.

#### COUNCIL AUTONOMY

The Illinois Council became its own designated state agency in 1990 and since then we have certainly seen a great improvement in our ability to advocate for inclusion in state programs and in communities throughout our state. It has particularly helped us gain authority over our own staff, which was not the case before we became our own agency.

While independent status is not feasible for every Council at this time, many of the provisions you propose will enable Councils to operate free of inappropriate influence from and control by the State.

#### COUNCIL FLEXIBILITY AND EMPOWERMENT ACTIVITIES

One of the best things about the Council program is the flexibility Congress has given us to design activities most suited to our own needs and priorities in the states and territories. This flexibility allows our programs to innovate, to try things that, if successful, lead the developmental disabilities movement into the future. In recent years, Councils have been leaders in supporting people with developmental disabilities and family members to control our own lives and become involved in the decisions that directly affect us.

Your suggested changes to the Act, including the use of "people first" language, reinforce this commitment to me and my son and all other families who experience developmental disabilities.

In Illinois, we have made a large investment in empowerment activities. We fund several People First organizations and support local training in self-advocacy for parents who then train other parent-advocates. Councils, including the Illinois Council, have been leaders in the family support movement, developing and supporting passage of state family support legislation. The Illinois Council sponsored a national meeting of parents who developed a draft national policy on family support.

Also, my Council is working with our community college system to include more students with developmental disabilities. For several years we have had a housing initiative which enables people with developmental disabilities to own their own homes. Our Council has provided technical assistance to other Councils to start similar housing initiatives.

Empowerment is central to Councils' mission. At least one half of our members are people with developmental disabilities and family members. I'm pleased to say that our Council has done a good job in recruiting Council members with disabilities, including people with cognitive disabilities. Councils provide supports to members with disabilities to ensure they give their best to Council deliberations. My Council has assigned specific staff people to be liaisons to our members with disabilities, assisting them to prepare for committee and Council meetings and ensuring that they get whatever personal assistance they need. Councils particularly need the provision you propose which enables us to fund supports, such as personal assistance services, for our consumer members while doing Council business. In some states, the inability to use Basic State Grant funds in this way has been a barrier to including more people with severe disabilities on our Councils.

Our council successfully supported legislation mandating that people with disabilities and family members be appointed to various state boards and commissions, further empowering people with developmental disabilities to have control over the services and supports they receive. I understand that many other Councils have similar initiatives.

I'd like to especially thank you for the way you have reorganized the Act. Because the DD Act is a major educational tool for Council members, service providers, and policy-makers at all levels, you have made it easier to understand this small, but complicated, program.

#### COUNCIL ACCOUNTABILITY

Another area the subcommittee bill addresses is Council accountability. The provision which addresses Council vacancies is very important, since too often it takes months for new appointments to be made, preventing Councils from having the quorum needed to conduct business. Since many vacancies occur because consumer members rotate off Councils, sluggish appointments keep the voices of people with disabilities and their family members from being heard. The Subcommittee's changes to require the Council to report to the Secretary of HHS if there are significant delays in making appointments will help Councils solve this problem.

Another provision which will help Council's accountability is requiring each Council to have conflict of interest policies. My Council already has such policies and I know from experience that it has been helpful for all of us to be clear on what is and what is not permissible and what actions may appear to place us in a conflict situation.

#### COUNCIL SYSTEMS CHANGE ACTIVITIES FOR PEOPLE WITH DISABILITIES

I'd like to address the issue of Council work on behalf of people with disabilities other than developmental disabilities. I believe all Councils do this to a greater or lesser degree as we support communities to include people with developmental disabilities. For example, when we work to make transportation systems and public accommodations accessible, all people with disabilities benefit, not only those with developmental disabilities.

Whether or not to change from a Developmental Disabilities Program to a Disabilities Program is a complex matter at the state level and the approach proposed by the subcommittee shows sensitivity to the difficulties involved. It needs to be remembered that people with developmental disabilities are vulnerable, unserved, underserved, segregated and excluded, sometimes neglected and abused. The DD programs are the only locus to redress these inequities and break down those social barriers. The reasons the Developmental Disabilities Act was needed in 1970 still exist and will continue to exist in 3 years.

The pilot projects and research initiatives under Projects of National Significance are critical to our understanding of what such a change might involve. I would urge you to do everything you can to ensure that there are sufficient resources to undertake these initiatives.

#### RESOURCE ISSUES

One more word on resources. In the early 1980s, Councils were asked to lower our expectations about funding and to be content with authorization levels that were closer to what could realistically be expected in appropriations. We did that.

However, during the last decade, the gap between authorization levels and appropriations has continued to widen. Our small program is increasingly relied upon as state and federal resources dwindle. The DD programs are among the very few investment programs created by Congress in the area of human services and the only ones targeted to people with developmental disabilities. The Basic State Grant Program needs an increased federal investment if our efforts are to continue to be innovative and build the capacity of states and communities to support and include people with developmental disabilities in all aspects of American life.

On behalf of all Councils, particularly the citizen volunteers who serve on Councils whose lives are so directly affected by disability policy, I strongly urge you to be our ambassadors to your colleagues in the Senate to fully fund the Basic State Grant program at the level recommended by the Consortium for Citizens with Disabilities and to strongly advocate to keep this level when the House and Senate conference on this program. A former Chairman of this subcommittee used to refer to the funds for the DD programs as "decimal dust." Please help us ensure that the relatively small increases we have recommended are not swept away, like dust, in the rush to cut the deficit.

Thank you very much for this opportunity to testify on behalf of the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act.

Senator HARKIN. Thank you very much, John. I'll go on through the panel, and then we'll get to questions.

Sara Wiggins-Mitchell is director of the protection and advocacy system in New Jersey and the current president of the National Association of Protection and Advocacy Systems.

Welcome, Sara.

Ms. WIGGINS-MITCHELL. Good morning, Chairman Harkin and members of the committee.

I am Sara Wiggins-Mitchell. I am president of the National Association of Protection and Advocacy Systems, which is the national voluntary membership organization of P and As for individuals with developmental disabilities and mental illness and client assistance programs.

I am also the director of the Division of Advocacy for the Developmentally Disabled in New Jersey's Department of the Public Advocate, which is New Jersey's designated P and A for individuals with developmental disabilities.

I first want to thank you for the opportunity to be here on behalf of NAPAS to testify on the discussion draft of the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. I will simply supplement our written testimony by focusing on several of the issues which the member organizations of NAPAS believe are of critical importance.

Several of the new provisions of the discussion draft will strengthen our ability to protect the rights of individuals with disabilities. One such provision which I would like to specifically mention allows P and As to have access at reasonable times and locations to eligible individuals residing in residences providing services, support, and other assistance. Currently, we can only serve individuals who actually request our services. Unfortunately, many of those individuals we are mandated to serve are unable to do so, and in many instances, it is actually family members or professionals, or even staff of the facility, who may request our services.

There is language in the draft bill which is based on language already in the Social Security Act which gives the P and A access to individuals who are eligible for P and A services. Just as under OBRA 1987, we are granted access to all eligible individuals residing in nursing homes.

Equally significant for P and As and those we serve is also a provision in the draft reauthorization which permits P and As to pursue appropriate remedies in our own names when the individual or individuals on whose behalf we are acting are unable to do so. This is a particularly critical provision of the proposed draft, because there are persons living in facilities subject to abuse and neglect who may be too frightened to contact us and request services when in fact the individuals they are complaining about are the very individuals upon whom they must depend for their daily needs. And in fact, we have just recently received a case from the Texas P and A which provides even more vivid illustration as to why this provision is necessary.

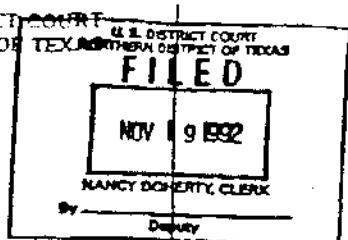
In this particular case, the P and A was unable to pursue vindication of some very important rights under the Fair Housing Act when the individual and his family chose not to pursue the vindication of the individual's rights because of fear of what would happen to the individual if they did so.

I would like to submit this case for the record if I may do so.

Senator HARKIN. Absolutely. Without objection, we will include it.

[Document follows.]

IN THE UNITED STATES DISTRICT COURT  
FOR THE NORTHERN DISTRICT OF TEXAS  
DALLAS DIVISION



MATT W., by JUDI CHAMBLEE,  
Guardian; THE ASSOCIATION FOR  
RETARDED CITIZENS OF DALLAS;  
and ADVOCACY, INCORPORATED,

Plaintiffs,

VS.

DALLAS COUNTY MENTAL  
HEALTH AND MENTAL  
RETARDATION CENTER BOARD  
OF TRUSTEES, et al.,

Defendants.

Civil Action No. 3:92-CV-0879-D

MEMORANDUM OPINION  
AND ORDER

Plaintiffs Matt W., by Judi Chamblee, Guardian ("Matt W."), the Association for Retarded Citizens of Dallas ("ARC"), and Advocacy, Incorporated ("Advocacy") bring this action for declaratory relief, permanent injunctive relief, and damages pursuant to the Fair Housing Act of 1968, as amended by the Fair Housing Amendments Act of 1988 (the "Act" or "Fair Housing Act"), 42 U.S.C. § 3601 et seq. and 42 U.S.C. §§ 1983, 1985, and 1986. Defendants move pursuant to Fed. R. Civ. P. Rule 12(b)(1) to dismiss the suit for lack of standing. Plaintiffs move for leave to amend their complaint. For the reasons that follow, the court grants plaintiffs leave to amend their complaint, dismisses Advocacy's claims, dismisses in part ARC's claims, and otherwise denies the motion.

Plaintiff Matt W. is a minor with mental retardation and cerebral palsy. ARC is an organization that advocates on behalf of persons with mental retardation in the Dallas area. Advocacy is the state-wide protection and advocacy office established pursuant to 42 U.S.C. § 6041 that advocates for the rights of persons with developmental disabilities. Matt W. was a resident of a large residential facility serving children with developmental disabilities. Compl. at ¶ 16. In April 1991 the Texas Department of Mental Health and Mental Retardation decided to close the facility and move the children into small group homes located in the community. Id. Defendant Dallas County Mental Health and Mental Retardation Center Board of Trustees (the "Board") agreed to be responsible for development of three homes in Dallas County. Id. The Board purchased two property sites for

construction of two of the homes. *Id.* at ¶ 17. One of these sites is located at 5440 McShann Road, Dallas, Dallas County, Texas ("McShann Group Home"). *Id.* Defendant McShann Road Neighborhood Association (the "Association"), composed of residents of McShann Road, objected to construction of a group home for persons with disabilities. *Id.* at ¶ 18. In response, the Board temporarily suspended development of the McShann Group Home. *Id.* at ¶ 21. On October 2, 1991 the Board rejected an offer from the Association to purchase the property from the Board and voted to proceed with the construction. *Id.* at ¶ 25. On April 8, 1992 the Board reversed itself, and voted to discontinue construction of the McShann Group Home and sell the property to the Association. *Id.* at ¶ 29.

Matt W. was identified as one of six children to be assigned to the McShann Group Home, which was to be completed by February 1992. *Id.* at ¶ 17. The large residential facility in which Matt W. resided was closed on February 29, 1992. Because construction of the McShann Group Home was halted, Matt W. and five other mentally retarded children were moved to a temporary home. *Id.* at ¶ 30. The Board has commenced construction of an alternate home in which to house Matt W. permanently. *Id.*

Plaintiffs allege the "unplanned and unnecessary move of the children to the temporary home . . . has caused irreparable injury to Plaintiff Matt W. and the five other children." *Id.* at ¶ 31. They allege that Matt W. has shown severe regression in the areas of self-help skills and ambulating with his walker. *Id.* Plaintiffs also allege that prevention of the development of the McShann Group Home will chill the development of future group homes in Dallas. *Id.* at ¶ 32.

Plaintiffs contend the Board's decision to retract the plan to construct the McShann Group Home and its decision to sell the property to the Association violates the Fair Housing Act, *id.* at ¶ 36, and that the Association's efforts to prevent the use of the McShann Road property as a home for persons with handicaps violates the Act. *See id.* at ¶ 38. Plaintiffs also sue the individual members of the Board, the Dallas County Commissioners Court, and two Dallas County Commissioners. They contend the Commissioners Court and County Commissioners engaged in a conspiracy to violate the Act. *Id.* at ¶¶ 40-43. Moreover, plaintiffs allege a conspiracy to deprive plaintiffs of their civil rights pursuant to 42 U.S.C. §§ 1983, 1985, and 1986. *Id.* at ¶ 45. Plaintiffs ask the court to order the Board to pursue

development of the McShann Group Home, and to enjoin the defendants from interfering and blocking the Home's development. Plaintiffs also seek damages for violations of the Act and deprivations of their civil rights.

Defendants move to dismiss, contending plaintiffs do not satisfy the Article III constitutional requirements for standing. Defendants contend ARC and Advocacy have standing neither as organizations in their own right nor as representatives to bring suit on behalf of their members. They argue that Matt W. does not have standing because he cannot demonstrate that his alleged injuries will be redressed by a favorable decision.

## II

Plaintiffs moved to amend their complaint after defendants moved to dismiss this action but before defendants filed their reply brief. The amended complaint adds the Dallas County Mental Health and Mental Retardation Center (the "Center") as a defendant, purports to correct a few statements of fact, and seeks damages from all defendants. Mot. to Am. Compl. at 2. Defendants' reply to plaintiffs' response to the motion to dismiss addresses the injuries alleged in the proposed first amended complaint. D. Rep. Br. at 5 n.1. The court holds that allowing plaintiffs to amend the complaint will not unduly surprise or prejudice the parties and, accordingly, grants plaintiffs leave to amend. Therefore, the merits of defendants' motion to dismiss are considered as they relate to the first amended complaint.

## III

The court now turns to defendants' standing arguments. Standing to sue under § 812 of the Fair Housing Act, 42 U.S.C. § 3612,<sup>1</sup> extends to the full limits of Article III. *Havens Realty Corp. v. Coleman*, 455 U.S. 363, 372 (1982). "Thus the sole requirement for standing to sue under § 812 is the Art. III minima of injury in fact: that the plaintiff allege that as a result of the defendant's actions he has suffered 'a distinct and palpable injury.'" *Id.* (citation omitted). The test requires the court to examine (1) whether the alleged injury is "distinct and palpable;" (2) the causal connection between the defendant's conduct and the alleged injury; and (3) the causal connection between the alleged injury and the relief sought. *Hanson v. Veterans Admin.*, 800 F.2d 1381, 1384 (5th Cir. 1986). Moreover, for the purposes of ruling on a motion to dismiss for lack of standing, the court

<sup>1</sup>42 U.S.C. § 3612, Enforcement by Private Person, is now 42 U.S.C. § 3613.



must accept as true all material allegations of the complaint and construe the complaint in favor of the complaining party. Warth v. Seldin, 422 U.S. 490, 501 (1975).

## A

The court first considers whether Matt W. has standing to sue. Defendants contend Matt W. does not have standing because he cannot make the requisite demonstration of redressability. A plaintiff must allege personal injury "likely to be redressed by the requested relief." Allen v. Wright, 468 U.S. 737, 751 (1984). Defendants concede that Matt W. has standing to maintain a claim for damages. D. Rep. at 17 n.6. They nevertheless contend Matt W.'s injuries will not be redressed by granting an injunction and forcing the building of the McShann Group Home because plans are underway to construct a group home at another location. Mot. Dis. at 8. The court disagrees.

Matt W. alleges his rights were violated under the Fair Housing Act because defendants prevented him from living in a permanent group home located on McShann Road. According to plaintiffs, defendants violated the Fair Housing Act by making the dwelling unavailable based on Matt W.'s handicap. See Compl. at ¶¶ 33-39. Matt W. has unquestionably alleged an injury. Moreover, this injury has not been redressed in that Matt W. is not presently living in a permanent group home or in a home located on McShann Road. Matt W. seeks a declaration that defendants' actions violated the Act. He also requests a permanent injunction ordering defendants to pursue development of the McShann Group Home and enjoining defendants from opposing the development of the Home. An injunction is a proper remedy for a Fair Housing Act violation. See, e.g., Hanson, 800 F.2d at 1386.

It is important to note that the essence of standing is whether the litigant is entitled to have the court decide the merits of the dispute. Id. at 1385 (quoting Warth, 422 U.S. at 498). "It is inappropriate for the court to focus on the merits of the case when considering the issue of standing." Id. (citing O'Hair v. White, 675 F.2d 680, 685 (5th Cir. 1982)). The determination to be made is whether the prospect for obtaining relief from the injury as a result of a favorable ruling is too speculative. Id. The court finds it is not. Accordingly, Matt W. has standing to assert his claims for violations of the Act and of his civil rights.

## B

The court next addresses whether ARC and Advocacy have standing to sue. "[A]n association may have standing in its own right to seek judicial relief from injury to itself and

to vindicate whatever rights and immunities the association itself may enjoy. Moreover, in attempting to secure relief from injury to itself the association may assert the rights of its members, at least so long as the challenged infractions adversely affect its members' associational ties." *Worth*, 422 U.S. at 311. "Even in the absence of injury to itself, an association may have standing solely as the representative of its members." *Id.*

In order for an organization to establish that it has standing to sue in its own right, it must allege such a personal stake in the outcome of the controversy as to warrant its invocation of federal court jurisdiction. *Havens*, 455 U.S. at 378-79. Simply alleging a setback to the organization's abstract societal interests is not enough. *Id.* at 379. The Supreme Court has recognized that an association has standing to sue on behalf of its members when "(a) its members would otherwise have standing to sue in their own right; (b) the interests it seeks to protect are germane to the organization's purpose; and (c) neither the claim asserted nor the relief requested requires the participation of individual members in the lawsuit." *Hunt v. Washington State Apple Advertising Com'n.*, 432 U.S. 333, 343 (1977).

1

Defendants contend ARC does not have standing to sue in its own right because it has not suffered injury in fact. They also argue that ARC does not have representative standing on behalf of Man W. Plaintiffs respond that ARC has suffered injury in fact because of a loss of financial resources and frustration of the organization's purpose as a result of defendants' actions.

ARC's stated mission "is to improve the quality of life of persons with mental retardation and related developmental conditions and to reduce the incidence and limit the consequences of these conditions." P. Resp. Mot. Dism. Ex. C. To accomplish this, ARC "acts as an advocate for such persons, provides support to them and their families and promotes awareness and acceptance of them in the community." *Id.* Plaintiffs contend the intense and concerted effort by ARC to advocate for the rights of persons with mental retardation to live in the community of their choice and for the construction of the McShann Group Home has cost it dearly in terms of lost staff time and actual money. *Id.* at 16-17.

ARC has failed, however, to allege injuries that constitute more than a setback to the organization's abstract societal interest.

In Hayens the Court found concrete and demonstrable injuries because the defendants impaired an organization's ability to provide counseling and referral services. 455 U.S. at 379. These services were specific activities provided by the organization. ARC has not alleged injury to any specific service it provides. See, e.g., Colorado Taxpayers Union, Inc. v. Romer, 963 F.2d 1394, 1397 (10th Cir. 1992) (organization did not have standing to sue where injury could not be tied directly to concrete harm inflicted upon primary activity of plaintiff organization, as in Hayens).

In Cleburne Living Center, Inc. v. Cleburne, 726 F.2d 191, 203 (5th Cir. 1984), aff'd in part and vacated in part on other grounds, 473 U.S. 432 (1985), the Fifth Circuit affirmed the district court's finding of no standing to an association of retarded citizens who sued in their own right and as a representative of its members. The association's activities included promoting the general welfare of mentally retarded people, fostering the development of programs on their behalf, and advising and aiding parents of mentally retarded persons in the solution of their problems in this area. Id. After setting out the two requirements for standing, the court stated the association had not proved any drain on its resources. Id. Although the association favored the development of a group home and the city council's decision impaired that interest, the injury to the association's "abstract social interests" was too intangible to demonstrate standing. Id. (citing Hayens, 455 U.S. 363).

The activities alleged by ARC are almost identical to those of the association in Cleburne Living Center. ARC has also alleged, however, a drain on its resources. It contends it lost staff time and money by attending public meetings, preparing for and speaking at such meetings, responding to questions about this situation, and meeting with counsel to discuss options for legal action. P. Resp. Mot. Disn. at 17. These resources were spent fighting the opposition to the McShann Group Home. Notwithstanding this, an organization cannot manufacture the injury necessary to maintain a suit from its expenditure of resources on that very suit. Spann v. Colonial Village, Inc., 899 F.2d 24, 27 (D.C. Cir. 1990). "Hayens makes clear ( ) that an organization establishes Article III injury if it alleges that purportedly illegal action increases the resources the group must devote to programs independent of its suit challenging the action." Id. ARC has not demonstrated this and,

accordingly, has not established standing to sue in its own right. ARC's claims that are alleged in its own right are dismissed.

2

Even if ARC has suffered no injury, plaintiffs contend that because Matt W. is a member of ARC, ARC can assert his rights. The court is uncertain, however, whether plaintiffs allege that Matt W. is a member of ARC or that Matt W. is a member through his mother and guardian.<sup>7</sup> ARC's bylaws may provide that Matt W. is a member by virtue of his mother's membership. Whether Matt W. is a member of ARC is dispositive of ARC's right to assert his interests. If Matt W. is not a member, ARC does not have representational standing.

Assuming Matt W. is shown to be a member of ARC, ARC will have satisfied the first prong of the *Hunt* test for representational standing. The second prong of the test will also be satisfied because the interests ARC seeks to protect are germane to the organization's purpose. ARC is advocating on Matt W.'s behalf in securing his placement in a permanent group home. Group homes have been recognized as an essential ingredient of normal living patterns for persons who are mentally retarded. Opposition to the establishment of group homes operates to exclude persons who are mentally retarded from the community. Cleburne Living Center, 726 F.2d at 193. This certainly is germane to ARC's purpose of improving the quality of life of persons with mental retardation and promoting awareness and acceptance of them in the community.

ARC would satisfy in part, and not meet in part, the last prong of the *Hunt* test. ARC cannot represent Matt W. on his claims for monetary damages because this would require the participation of Matt W. in the suit. Whenever an injury is peculiar to the individual member concerned and would require individualized proof, an organization will not have standing to claim damages on the member's behalf. See Worth, 472 U.S. at 515-16. Matt W. asserts he has suffered irreparable injury in the form of emotional distress and educational development as a result of violations of the Fair Housing Act and of his civil rights. Compl. at ¶ 31. Matt W. seeks damages for these deprivations. These rights and

<sup>7</sup>In the complaint, plaintiffs do not allege that Matt W. is a member; they allege that his mother and guardian is a member. Compl. at ¶ 14. In the motion to dismiss, plaintiffs state that both Matt W. and his mother are members of ARC. P. Resp. Mot. Dis. at 16. Later in the response, they contend Matt W., through his mother, is a member of ARC. Id. at 22.

the relief requested are personal to Matt W. and require his individualized participation. Therefore, ARC does not have standing to assert a damages claim on Matt W.'s behalf.

ARC can represent Matt W., however, in claims for declaratory relief and for a permanent injunction. As the Court pointed out in Warth, "in all cases in which we have expressly recognized standing in associations to represent their members, the relief sought has been of this kind." 422 U.S. at 515. Because Matt W. has been shown to have standing to assert these claims, ARC has representational standing to do so on Matt W.'s behalf.<sup>3</sup> ARC will remain in the suit in its representative capacity and will not be entitled to claim damages. See *id.* at 515 (association had no standing to claim damages on its own behalf because injuries suffered were peculiar to individual members); see also Minority Employees of the Tenn. Dep't of Employment Sec., Inc. v. Tennessee, Dep't of Employment Sec., 573 F.Supp. 1346, 1350 (M.D. Tenn. 1983) (organization had no standing to assert claims where suit brought in representational capacity based on injuries to others).

Because of the inconsistencies in plaintiffs' allegations on the issue of Matt W.'s membership status, the court will not decide whether Matt W. can claim membership in his own right or through his mother and guardian. The court will grant plaintiffs the opportunity to amend their complaint to clarify this matter. Defendants may again move to dismiss if the amended complaint reflects that ARC does not have standing, in whole or in part.

## 3

Advocacy argues it has standing to sue in its own right. Pursuant to federal statute, Advocacy has the authority to pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of persons with developmental disabilities. 42 U.S.C. § 6042(a)(2)(A)(i) (Supp. 1992). To sue in its own right, Advocacy must also show that it has suffered an injury in fact. See Mississippi Protection & Advocacy Sys., Inc. v. Cotton, 929 F.2d 1054, 1058 n.3 (5th Cir. 1991) (citing Developmental Disabilities Advocacy Center, Inc. v. Melton, 689 F.2d 281, 287 (1st Cir. 1982) (group created pursuant to federal statute to advocate rights of persons with developmental disabilities had to show injury in fact to establish standing)).

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<sup>3</sup>Insofar as plaintiffs request relief only with respect to the McShann Group Home and Matt W. has been shown to have standing to assert these claims, ARC is not needed to assert these rights. The court will nevertheless allow ARC the opportunity to establish its representational standing.

"The mission of Advocacy, Inc. is to advocate, protect and advance the legal, human and service rights of people with disabilities." P. Resp. Mot. Dis. Ex. E. This interest is even more general and abstract than the interest asserted by ARC. Like ARC, plaintiffs allege that Advocacy "has expended extensive resources in advocating for and filing suit against Defendants for their violations of the [Fair Housing Act] and the Civil Rights Act, 42 U.S.C. §§ 1983, 1985 and 1986." *Id.* at 21. Moreover, like ARC, Advocacy has not established an injury in fact and has not shown the court to have standing to sue in its own right. *See* discussion *supra* § III(B)(1).

4

Advocacy does not have standing to sue on behalf of Matt W. because he is not a member. Plaintiffs admit that Advocacy is not a traditional membership organization. P. Resp. Mot. Dis. at 19-20. Relying on *Hunt*, plaintiffs contend that all persons with mental retardation in Texas are members of Advocacy, including Matt W., because Advocacy represents the legal rights of all such Texans. *Id.* at 20. The court disagrees.

In *Hunt* the Court addressed whether an apple advertising commission's status as a state agency precluded it from asserting the claims of the Washington apple growers and dealers who formed its constituency. *Hunt*, 432 U.S. at 344. The Court held the commission had standing to bring the action in a representational capacity. Relevant to the Court's determination was the fact that the apple growers possessed all the indicia of membership in an organization: "[t]hey alone elect members of the Commission; they alone may serve on the Commission; they alone finance its activities, including the costs of this lawsuit, through assessments levied upon them." *Id.* at 344-45. By contrast, mentally retarded citizens, specifically Matt W., do not possess such "indicia of membership" in Advocacy. Plaintiffs assert that Advocacy's board of directors is appointed by 2 organizations of people with disabilities, including ARC, and it has three advisory councils comprised predominantly of persons with disabilities and family members of persons with disabilities. P. Resp. Mot. Dis. Ex. F at 2. Yet this does not establish the "indicia of membership" as found in *Hunt* to allow it to claim all mentally retarded Texans as "members." Plaintiffs have not shown how Matt W. possesses an "indicia of membership" where he does not directly elect any member to Advocacy's board, does not serve on the board, and has not financed any activities of Advocacy. Accordingly, Matt W. is not shown to be a member, and Advocacy does not have representational standing to assert his rights.

The court grants plaintiff's motion for leave to file their first amended complaint. The clerk shall file the amended complaint today. Defendants' motion to dismiss for lack of standing is granted as to Advocacy and as to ARC, to the extent it sues in its own right. The court grants the remaining plaintiffs 20 days from the date of this order to amend their complaint regarding ARC's representational standing on behalf of Max W. In all other respects, defendants' motion is denied.

SO ORDERED.

November 19, 1992.

*Sidney A. Fitzwater*  
SIDNEY A. FITZWATER  
UNITED STATES DISTRICT JUDGE

IN THE UNITED STATES DISTRICT COURT  
FOR THE NORTHERN DISTRICT OF TEXAS  
DALLAS DIVISION

U.S. DISTRICT COURT  
NORTHERN DISTRICT OF TEXAS  
**FILED**  
MAY 11 1993

THE ASSOCIATION FOR RETARDED  
CITIZENS OF DALLAS,

Plaintiff,

vs.

DALLAS COUNTY MENTAL  
HEALTH AND MENTAL  
RETARDATION CENTER BOARD  
OF TRUSTEES, et al.,

Defendants.

NANCY DOHEERTY, CLERK

By Deputy

Civil Action No. 3:92-CV-0879-D

MEMORANDUM OPINION  
AND ORDER

Defendants move to dismiss plaintiff's second amended complaint, contending plaintiff lacks standing. For the reasons set out below, the court converts the motions to motions for summary judgment and dismisses the action without prejudice.

1

The relevant background facts have been set out in a prior opinion of the court. In sum, plaintiff The Association for Retarded Citizens of Dallas ("ARC"), and two other plaintiffs, brought suit against the defendants for their actions in connection with the operation of a group home for mentally retarded children (the "McShann Group Home"). Defendants moved to dismiss their action on the ground that the plaintiffs lacked standing. The court granted in part and denied in part that motion. In the November 19, 1992

opinion, the court held that plaintiff Matt W.<sup>1</sup> had standing to sue, but dismissed the claims of plaintiff Advocacy, Incorporated. *Op.* at 13-14. The court held that ARC did not have standing to sue in its own right, *id.* at 9, but concluded that ARC may have standing to sue on behalf of Matt W. *id.* at 11. The court ordered ARC to replead and clarify whether it had representational standing. *Id.* On December 11, 1992 Matt W. was dismissed as a plaintiff because he no longer desired to pursue the case. ARC - now the sole remaining plaintiff - filed its second amended complaint on December 22, 1992. Defendants move to dismiss ARC's second amended complaint asserting again that it lacks standing.<sup>2</sup>

## II

An association may have standing to sue on behalf of its members. The requirements for representational standing are familiar. See *id.* at 7. The first requirement the association must satisfy is that one of its members otherwise has standing to sue in his own right. *Elliott v. Washington State Apple Advertising Com'n.*, 432 U.S. 333, 343 (1977). The court earlier held that the determination whether Matt W. is a member of ARC is dispositive of ARC's right to assert his interests. *Op.* at 9.

In its second amended complaint, ARC alleges it has representational standing by virtue of the fact that the mother of another child who was scheduled to move into the McShann Group Home - Jeffrey J. - is a member of ARC. See 2d Am. Compl. at ¶ 33.

In its response to the motions to dismiss, ARC also asserts that Matt W. is a member of ARC through a complimentary membership sent to his mother and him in September 1992. Defendants deny that Jeffrey J. and Matt W. are members of ARC.<sup>3</sup>

<sup>1</sup>Matt W. was represented by his guardian, Judi Chamberlin.

<sup>2</sup>One group of defendants filed a motion to dismiss plaintiff's first amended complaint. Because ARC has filed a second amended complaint, this motion is denied. This same group of defendants also filed a motion for summary judgment. By March 1, 1993 order, defendants Joyce Brown, Sheryl Howard, Agnes Whitley, M.D., and Paula Dobbe-Wiggins have been dismissed from the action.

<sup>3</sup>In support of their motions to dismiss, defendants have attached affidavits from the mothers of Jeffrey J. and Matt W. Because the court has considered affidavits submitted by the defendants in deciding whether ARC has standing, the court will treat the pending motions as motions for summary judgment. See *Cramer v. Skimmig*, 931 F.2d 1020, 1025 n.3 (5th Cir.), cert. denied, \_\_\_ U.S. \_\_\_, 112 S.Ct. 294 (1991). The standard for deciding a challenge to standing on a motion for summary judgment differs from the standard applied to a Fed. R. Civ. P. 12(b) motion. The question becomes whether a genuine issue of fact exists on the standing issue. *Id.* One group of defendants moved for summary judgment on March 19, 1993. In this motion the defendants reassert their challenge to ARC's standing to sue. ARC has therefore had an adequate opportunity to respond to the presentation of evidence outside the pleadings, and to treat the motions as seeking summary judgment on the issue of standing.



## A

ARC contends Jeffrey J. is a member by and through his mother's membership, which she initiated in February 1991 and renewed in February 1992. ARC posits that its definition of "member" includes each person in the member's family, especially the family member with mental retardation, and that each person in the member's family receives the full benefits of membership except the right to vote. Jeffrey J.'s mother, Paula Thompson ("Thompson"), refutes this assertion. She contends she joined ARC only as an individual. Thompson *aff.* at ¶ 8. Thompson states that Jeffrey J. has not joined ARC. *Id.* at ¶ 9. In addition, she points out that Jeffrey J. is 18 years of age and that she is not his legal guardian. *Id.* at ¶ 10. Thompson avers that she had no prior knowledge that ARC had made allegations regarding her or Jeffrey J. in its complaint. *Id.* at ¶ 6. Moreover, she does not wish to participate in this lawsuit, *id.* at ¶ 7, and has asked ARC to remove from the complaint all references to her and Jeffrey J. *Id.* at ¶ 11.

ARC contends Matt W. is also a member through his mother's complimentary membership, as well as his own complimentary membership. Nevertheless, Matt W.'s mother, Judi Chamblee ("Chamblee"), has stated that she and Matt W. were not members at the time this lawsuit was filed and are not presently members of ARC. Chamblee *aff.* at ¶¶ 5, 6. According to Chamblee, she and Matt W. have never been members of ARC. *Id.* at ¶¶ 5, 6. She admits she received a membership application form from ARC three months after the lawsuit was filed, but never applied for membership as an individual or on behalf of Matt W. *Id.* at ¶ 7. ARC responds that under its policies and practices, membership is effective until the member terminates it. ARC asserts, therefore, that Chamblee remained a member because she never refused the complimentary membership or notified ARC, and that Jeffrey J. is a member because his mother has not communicated a desire to have Jeffrey J.'s membership terminated.

Standing determines whether a litigant is entitled to have the court decide the merits of a dispute or of a particular issue. *Worth v. Sciffo*, 422 U.S. 490, 498 (1975). Standing is founded in the concern about the proper role of courts in a democratic society. *Id.* The jurisdiction of a federal court can be invoked only when the plaintiff himself has suffered some threatened or actual injury resulting from the putatively illegal action. *Id.* at 499. "The Art. III judicial power exists only to redress or otherwise to protect against injury to the complaining party, even though the court's judgment may benefit others collaterally." *Id.* In addition to Article III standing requirements, the Supreme Court has held that courts

should consider three prudential concerns in determining standing. *Cramer v. Skinner*, 931 F.2d 1020, 1024 (5th Cir.), cert. denied, \_\_\_ U.S. \_\_\_, 112 S.Ct. 298 (1991). One of these is whether a plaintiff is asserting his own legal rights and interests rather than the legal rights and interests of third parties. *Id.*

As a matter of prudence, the court holds that ARC does not have standing to assert the interests of Matt W. and Jeffrey J. This is not a case where Matt W. and Jeffrey J. are attempting to establish that they are members of ARC in order for ARC to represent their interests in this litigation. Similarly, this is not a case where Matt W. and Jeffrey J. have sought membership in ARC. In fact, the mothers of Matt W. and Jeffrey J. deny that Matt W. and Jeffrey J. are members. Rather, ARC apparently has attempted to manufacture standing in this action by bestowing complimentary memberships on unwilling potential plaintiffs in order to assert their rights and interests. Matt W., who has withdrawn as a party, and Jeffrey J. have not expressed an interest in having their rights represented by anyone in this case. In its discretion, the court will not allow an association to bootstrap its way into court in this manner. Accordingly, the court finds a prudential limitation on ARC's standing to bring the instant case.

#### B

ARC has also tried to establish that it has standing to sue by alleging that some of its members with mental retardation will need residential placement in group homes in Dallas during some period of their lives. 2d Am. Compl. at ¶ 33. Abstract injury is not enough, however, to satisfy the threshold requirement imposed by Article III that a plaintiff allege an actual case or controversy. *City of Los Angeles v. Lyons*, 461 U.S. 95, 101 (1983). "The plaintiff must show that he 'has sustained or is immediately in danger of sustaining some direct injury' as the result of the challenged [ ] conduct and the injury or threat of injury must be both 'real and immediate,' and not 'conjectural' or 'hypothetical.'" *Id.* at ¶01-02. The focus is on whether the injury or threat of injury is "sufficiently real and immediate to show an existing controversy." *See id.* at 103 (quoting *O'Shea v. Littleton*, 414 U.S. 422, 426 (1974)). The fact that the McShann Group Home was not built does not present a sufficiently real and immediate threat that persons with mental retardation will be deprived

placement in group homes in Dallas in the future.' Accordingly, ARC has also failed to establish that it has standing to sue on behalf of these hypothetical plaintiffs.

. . .

Defendants' motions for summary judgment are granted. By separate judgment, this action is dismissed without prejudice.

SO ORDERED.

May 19, 1993.

*Sidney A. Filzwater*  
SIDNEY A. FILZWATER  
UNITED STATES DISTRICT JUDGE

'ARC's admissions show there is no real and immediate threat to the placement of people with mental retardation in group homes in Dallas. In its second amended complaint, ARC points out that a group home on Forest Lane in Dallas has been constructed since the abandonment of the construction of the McShann Group Home and is being occupied. See 2d Am. Compl. at ¶ 28. It also appears that a group home has been constructed on a property in Dallas that was selected the same time as was the site on McShann Road. See D. Rep. (April 27, 1993) at 3.

IN THE UNITED STATES DISTRICT COURT  
FOR THE NORTHERN DISTRICT OF TEXAS  
DALLAS DIVISION

U.S. DISTRICT COURT  
NORTHERN DISTRICT OF TEXAS  
**FILED**  
MAY 19 1993  
NANCY DORRITY, CLERK  
By \_\_\_\_\_ Deputy

THE ASSOCIATION FOR RETARDED  
CITIZENS OF DALLAS,

Plaintiff,

Civil Action No. 3:92-CV-0879-D

vs.

DALLAS COUNTY MENTAL  
HEALTH AND MENTAL  
RETARDATION CENTER BOARD  
OF TRUSTEES, et al.,

Defendants.

**JUDGMENT**

For the reasons set out in memorandum opinions and orders filed November 19, 1992 and today, this action is dismissed without prejudice. Taxable costs of court are assessed against plaintiffs The Association for Retarded Citizens of Dallas and Advocacy, Incorporated, jointly and severally.

Done at Dallas, Texas this 19<sup>th</sup> day of May, 1993.

*Sidney A. Filzwater*  
SIDNEY A. FILZWATER  
UNITED STATES DISTRICT JUDGE

Ms. WIGGINS-MITCHELL. Also, there are instances where even if the individual does feel comfortable in contacting us to request services, they still may not want their identity known for the same reason. This is so even if it is a family member or a professional or, again, a staff person who may contact us.

Really, we would like to alleviate such concerns about retaliation, and in order to do so, the P and As need to be able to go into the facility just as the discussion draft provides and to investigate claims of abuse and neglect without having to identify the source of the complaint and then to be able to proceed in court as necessary.

In my remaining minute, I would like to briefly touch upon a concern that is not directly tied to the reauthorization, but certainly affects our ability as P and As to serve all who are eligible for and need our services. That concerns the issue of resources.

We recognize, Mr. Chairman, that the draft bill tends to hold harmless the P and A systems during very difficult budgetary times, and certainly the 2 percent set-aside for training and technical assistance will help ensure the stability of the system. However, unfortunately, under the complex formula for determining State allocations, double funding, as last year, means for many of those States actually decreased funding. And I should say that New Jersey has been one of those States to experience decreased funding. And last year, when there was level funding, there were in fact 21 States that received decreased funding.

I call it a variation of Murphy's Law in that what we find is that during our period of resource crunch, when we are not only trying to reach out to serve previously underserved and unserved populations, that we are faced with the resources not to be able to do so.

Also, the resource crunch comes at a time when, on the heels of the increased demands for our services has been driven up by passage of major civil rights legislation, such as the Fair Housing Act and the Americans with Disabilities Act. For many P and As, what this has meant is the need to prioritize cases, to maintain waiting lists, and in some instances not be able to serve individuals who are in fact experiencing serious rights violations.

Again, if I may just make parochial reference to my own State, in New Jersey, limited resources has seriously impeded our ability to provide very seriously needed services for border babies, infants who have been abandoned in hospitals because of their HIV/AIDS status and who, because they are potentially developmentally disabled, are in fact eligible for our services. Despite the fact that New Jersey ranks at the very top in terms of incidence of pediatric AIDS, we have been able to do little more than to acknowledge this problem.

Finally, one other comment in the resource area. I would like to note that with a modest increase in funding to \$24.5 million, there is a provision of the draft bill which would create a P and A system for the American Indian population in the Southwest. This would go into effect once the funding hits that level. Currently, the American Indian population is certainly eligible to receive services under the P and A system, but this has been a very difficult reality to achieve because of cultural, legal and geographic barriers.

Finally, I would like to assert one comment that I did not plan to assert because there seemed to be some questions raised about our comfort level with increased consumer participation and involvement. And I would like to certainly go on record stating very strongly that NAPAS and our member organizations are very pleased to see the increased involvement of consumers that would occur under the discussion draft.

I close by noting that the reauthorization presents the opportunity not only to strengthen the protection and advocacy system for individuals with developmental disabilities, but also to ensure that this program receives adequate funding.

Again, I want to thank you for the opportunity to appear before you this morning on behalf of NAPAS, and we have been pleased to be a part of the effort to enact this reauthorization and look forward to working with the committee again in the future.

Thank you.

[The prepared statement of Ms. Wiggins-Mitchell follows:]

#### PREPARED STATEMENT OF SARA WIGGINS-MITCHELL

Chairman Harkin, and members of the committee, good morning. My name is Sara Wiggins-Mitchell and I am the President of the National Association of Protection and Advocacy Systems (NAPAS). I am also the Director of the Division of Advocacy for the Developmentally Disabled in the New Jersey Department of the Public Advocate. This is the designated Protection and Advocacy agency for individuals with developmental disabilities for the State of New Jersey. Thank you for inviting me to present testimony on the Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act, the cornerstone of our nation-wide Disability Advocacy Network.

NAPAS is the national, voluntary-membership organization representing the protection and advocacy agencies for developmental disabilities and mental illness and Client Assistance Program for people with disabilities. As you know, our system has been established under a variety of Public Laws, including the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (P.L. 94-103), which we examine today, the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (P.L. 99-319), and the 1984 and 1992 Amendments to the Rehabilitation Act (P.L. 98-221). Our membership provides legal, administrative and other means of redress for over 200,000 individuals with disabilities.

You have asked me here today, Mr. Chairman, to respond to the Senate discussion draft of the DD Act. I have reviewed the draft in question, discussed it thoroughly with members and staff of NAPAS, and have found it to be a generally solid piece of legislation. We are pleased with several of the new components of the Act, especially within Part C, The Protection and Advocacy. If there is one concern I have, however, it is that of the resources available to the P&A system. While this is not directly tied to the authorization of the program, it is nonetheless important that I mention it here in light of the mandates required of the P&A agencies.

First, however, I would like to discuss the points we are very pleased with. There are several new provisions of the law which we feel will strengthen the DD P&A's ability to assure the full implementation of the rights for people with disabilities.

#### 1. Increased Consumer Involvement

We are very pleased with the increased consumer participation. Under this reauthorization, consumer involvement in Governing Boards, Advisory Councils, and Federal program reviews will enhance the system's responsiveness to their needs. The new language first broadens the participants on the Governing Board to include individuals with disabilities who are eligible for services from the P&A. It also includes individuals who have received or are currently receiving services of the P&A. Parents, guardians, advocates and others authorized to represent these individuals would also be permitted to serve on the Board. In the few states which have no multi-member Governing Board, an Advisory Council would be created to advise the system on the policies and priorities established by the P&A. The majority of individuals on the Advisory Council will be persons who are eligible for services.

Finally, the new language mandates that there must be notice to the public regarding any Federal programmatic or administrative review of the P&A. This notice would also solicit any comments the public may wish to make regarding the services and operation of the P&A agency. These public comments must be included in the on-site visit report developed by the Federal agency. In our view, these additions to the statute will greatly enhance consumer input into the operation and priority-setting of the Protection and Advocacy Agency in each state.

## 2. Access to Individuals

The proposed legislation will provide greater access to individuals in DD facilities. Often, it is the people who are least able to communicate with our advocates who have the greatest need of our services. Current law states that we are able to provide services to any individual who requests them. Unfortunately, far too many individuals are unable to make that simple request. Many times it is a health care professional, a family member or an employee of the facility who notifies us of an individual in need. Under the OBRA 1987, P&As were granted access to all individuals eligible for P&A services residing in nursing homes. The statutory language in the draft bill is based on the language already in the Social Security Act. The proposed language in the draft bill will give us the right to have access at reasonable times and locations to any resident with a developmental disability in a facility which provides services, support and other assistance to this individual. Too often we are forced to use precious resources to establish our ability to even reach a client in order to assist them. With this language those resources will be able to go directly to assisting people with disabilities.

## 3. Standing

Another important component of the new bill is the authority to pursue remedies in the name of the P&A agency in certain instances, which codifies the practices of several federal courts. Many times an individual suffering abuse or neglect in a facility is too frightened to request services when their daily living needs are dependent on the very people who might abuse them. Even when a resident has contacted the P&A or the P&A has become aware of the situation from a third party (parent, staff, other agencies), the client may be unwilling to press the claim if their identity becomes known. All too often, aggressive advocacy is hindered when the client is too fearful of retaliation to place his or her name in court records. Likewise, many people with developmental disabilities are intimidated by guardians who are appointed to protect their interests but may, in fact, be violating the rights of that individual. There have been instances where children with disabilities have no parents or guardians to speak for them, and are unable to speak for themselves. Also, adults with severe mental retardation are unable to speak for themselves, or are unable to retain legal representation. P&As must not only have the authority to go into the facility, without having to identify the resident as the source of the complaint, to investigate claims and reports of abuse and neglect. P&As must then have the ability to pursue the case in the courts, if necessary, in the name of the agency, so that residents will be able to report instances of mistreatment without fear of retaliation.

## 4. American Indian Consortium

Another provision of the draft bill that we strongly support is the provision of P&A services for large reservation populations through an American Indian Consortium. NAPAS and the P&As in the Southwest have worked for several years to increase the representation of American Indians on lands in New Mexico, Arizona, Colorado, and Utah. While these American Indians are eligible for services under the P&A System, isolation as well as geographic, cultural and legal differences prevent their receiving adequate advocacy services from the current P&A systems. This proposal would create a P&A system to provide services to the American Indians not now receiving our services. The proposal would go into effect when appropriations reached an amount of \$24.5 million.

## 5. Hold Harmless

The draft bill also attempts to preserve the stability of the system during tight budget years. As you may know, Mr. Chairman, there is a complex formula which determines the allotment in each state. Unfortunately, when the entire System receives level funding, the formula may shift just enough that several states will lose money despite the increasing demand for services. Last year's appropriations, in

fact, left 21 states at a lower level of funding than the year before despite the fact the Congress provided level funding.

#### 6. Confidentiality of Records

The subcommittee draft reaffirms the importance of client confidentiality. In last year's reauthorization of the Rehabilitation Act, this subcommittee adopted language which prohibited the Administration from requiring a program to disclose the identity of an individual seeking services under the Client Assistance Program and the Protection and Advocacy for Individual Rights program, or any information which would be personally identifiable. This language has been added to this program today and we strongly support the addition.

#### 7. Training and Technical Assistance

A further important addition in this reauthorization is the two percent set-aside for training and technical assistance. A similar provision within both the Protection and Advocacy for Individuals with Mental Illness Act and the Protection and Advocacy for Individuals Rights program has proven to be invaluable in assisting PAIMI advocates to keep up-to-date in the areas which affect their work. This training and technical assistance component in the DD Act will provide the same opportunity for DD Advocates as well. Not only will they have the opportunity to participate in trainings, but the technical assistance to be provided will enable them to contact the T/A agency and have immediate assistance in working through a problem they may be having on a given issue. The set-aside will take effect if the appropriations reach a level of \$24.5 million. This ensures that no program will suffer a loss of funds which might adversely affect services to clients.

#### 8. Technical Changes

A. The proposed bill reduces certain administrative burdens by removing the need for assurances on issues that are more effectively addressed by statements of authority. These changes will not affect the important principles of independence and non-supplementation of funds. It will also allow the federal administering agencies to hold the programs directly responsible for enhanced independence.

B. Also, in this time of budget crunch and fiscal frugality, several P&A agencies housed within State agencies have been impacted by State restrictions on hiring, travel and trainings, even though the funds provided are Federal and no savings to states would be realized. New language in the Act will make sure that agencies will have sufficient staff and freedom to provide them with the training they require to carry out the mission of the P&A System.

#### 9. Inadequate Resources

Lastly, the most critical issue for people with developmental disabilities is the lack of adequate resources available to fulfill the P&A mandate. Regrettably, the P&As have had to prioritize cases, establish waiting lists, and turn away eligible people with very serious rights violations. We simply do not have the resources available to assist every eligible individual who comes to our door, let alone the individuals in institutions who are easily forgotten and who suffer major infringements of their rights. This reauthorization should serve as a vehicle not only for strengthening the program, but also as a reminder to Congress of the need to adequately fund this small but crucial program.

Thank you again Mr. Chairman and Members of the Committee for allowing me to present our views on the Reauthorization of this important piece of legislation. NAPAS has been pleased to work with this committee on behalf of the millions of Americans with disabilities, and we look forward to working closely with the Subcommittee in the future. I am now happy to answer any questions you may have for me.

Senator HARKIN. Thank you very much for being here and for your testimony.

Next is Ann Rhodes, a university administrator and pediatric nurse with a law degree. Ann has worked closely with the Iowa university-affiliated program to facilitate the integration of the program into the university and to support the efforts to be responsive to the needs in the community. Dr. Healy is director of the Iowa

university-affiliated program, and he has testified before this committee on several occasions in the past.

Welcome again, and please proceed.

Ms. RHODES. Thank you, Senator.

As you said, my name is Ann Rhodes. I am a pediatric nurse and an attorney, currently vice president for university relations at the University of Iowa.

It is my pleasure to have the opportunity to speak to you today on behalf of the United States 57 university-affiliated programs. As you know, the system of UAPs was established in 1970 with the goal of promoting productivity, independence, and community integration of all persons with disabilities. This is an important goal and a compelling goal. As you have heard from some of the testimony this morning, it is a goal that we are at least aiming toward reaching.

I'd like to say a few words about Iowa's program, recognizing that the role of the UAPs is to put into place a system and the pieces that will support this ultimate goal of integration of disabled persons into the community of their choice.

The University of Iowa has had well-developed and effective programs for providing clinical services to people with disabilities for over 45 years. It became a UAP in 1972, and at that point, its mission was enlarged and expanded to include the goal of supporting and facilitating the right of disabled persons to live independently in communities of their choosing. And we have made a number of important strides in the direction of that goal.

Iowa received a direct State appropriation for the clinical services that it provides. In addition, we receive a core administration grant of \$200,000 per year which enables us to leverage additional program dollars aimed at that goal. I think it is important to note that data which has been collected by the organization of UAPs has found that there is an average of \$28 returned on that \$1 investment through expanded services and training programs, and I think you are going to have a hard time finding any kind of a similar statistic regarding the cost-effectiveness of such programs.

The University of Iowa, which is a fine university, is extremely proud of the role and the accomplishments of its university-affiliated program and the role that the UAP plays in providing services for and advocacy on behalf of persons with disabilities. The parent universities of the other 56 UAPs are similarly proud.

You are aware that progress toward a goal is very gratifying, but true satisfaction only comes when that goal is reached. We are as yet and unfortunately far from the day when all persons with disabilities can feel pride in their roles as productive, independent members of the communities of their choice. Revisions in the current enabling legislation will permit the UAPs to be more efficient and more effective in working toward that ultimate goal.

Some of these revisions include an update of the definition of the UAPs. This new definition supports the current activities which are at the heart of the university's mission. These include the preparation of skilled professionals in a variety of different disciplines to go out and to be aware of the needs of persons with disabilities and to advocate on behalf of those needs. It also includes the dissemination of research findings, which can be applied to improve the care



and quality of life for persons with disabilities. It also includes assisting in the discovery and the transfer of new technology into community settings and in assisting community services in health, education and human services, particularly to reflect the state-of-the-art knowledge.

I can't really come up with a better model for the role of a research university and what a university should be doing in its State and its community. The combination of teaching, service, and state-of-the-art knowledge is an extraordinary one, and it is represented extremely well by the university-affiliated program. This reinforces the original wisdom of Congress when it placed all of these responsibilities directly in the heart of America's universities.

Despite a lot of progress, the tasks that I have described have not been completely completed, and we have a lot of work to do. There are still critical shortages, as you know, in a number of essential professionals, including occupational therapists, physical therapists, adequately educated physicians, and nurses. A fundamental change and a very important one is occurring in university training programs. There is a shift in the emphasis from service delivery in segregated settings to service delivery to persons with disabilities in community settings.

I can't emphasize strongly enough how important this is in terms of quality of life for disabled persons. It is essential that professionals be trained throughout their educational experience in the needs of persons with disabilities and how these needs can be met in communities.

Senator Harkin, prior to assuming my current responsibilities at the University of Iowa, I had the privilege of serving as the pediatric nursing supervisor at the University of Iowa Hospitals and Clinics. In fact, I remember showing you some of the university's outstanding pediatric inpatient facilities about 9 years ago. It was only too frequent, however, as we took care of children with severe illnesses and complex disabilities, that we saw these children go back to their communities only to have to return to the university hospital for basic medical care and treatment, treatment that could have been provided at a lower cost and much more convenient to the patients and families in their communities.

The training models that are used now in university-affiliated programs will enable our future therapists, nurses and physicians to understand and practice quality care in the communities in which people with disabilities live. Again, I can't emphasize the importance of this strongly enough. Community-based care is more humane, it is more cost-effective, and it is critical in the quality of life for persons with disabilities. The current UAP training model supports this goal.

In addition to skilled health care professionals, current support systems require technical assistance services to be available to persons, to communities, to systems. For many UAPs, it is the technical assistance provided to communities that has had the greatest impact on ensuring that local delivery systems can respond to the needs of persons with disabilities.

Finally, we feel that there are four priorities in the reauthorization act, and I would like to summarize each of these very briefly and speak to our support of them.

First is the priority of establishing a university-affiliated program in each State. I'd like to thank you, Senator Harkin, for your help and your advocacy in behalf of increasing this network. At this point, only Wyoming and the Virgin Islands are not included in it. We would like to see that network completed.

A second priority is placing a training program at each UAP. As an example of the importance of training programs, I'd like to cite two examples, one that was just completed at Iowa and one that is just underway.

Iowa has recently trained 900 direct care providers who care for persons with self-injurious behaviors. And if you have had any exposure to individuals with this type of behavior, you know that it is very frustrating, it is very difficult, and a little bit of training can make all the difference in the world in terms of the quality of care that is provided to this person as well as to the level of comfort that the family has in dealing with and the cost of taking care of that person. It is extremely laudable, I think, that we have taken care of 900 direct care workers in Iowa, but this is just the tip of the iceberg. A number more people need to be trained, and we have a program that will see to future training needs of people who take care of these patients.

Iowa's next program, one of the programs that is going into place right now, is really exciting. One of the themes that I have noted in listening to testimony of other witnesses today is that of advocacy as well as that of empowerment. These two issues are extremely important in providing care for persons with disabilities and for making sure that they achieve their potential.

Iowa is instituting a program that will train 250 disabled persons to act as their own advocates. And I can't tell you enough how excited I am about this program. I think this will, in your words, Senator Harkin, strengthen the consumer end as well as increase the level of knowledge of a lot of people about what disabled persons can do on their own behalf.

Finally, the addition of the ADA to the area of training in the reauthorization draft is really an excellent addition that is very important. Once the first and second priorities, that of completing the network and establishing a training program at each UAP, are achieved, the bill recommends increasing training awards from \$90,000 to \$100,000 for each UAP, and the fourth priority is to increasing core funding from \$200,000 to \$250,000 per year.

We support these priorities.

In summary, the Iowa university-affiliated program is proud of the progress it has made and pleased to report on some of its achievements which we think are quite representative of the network of UAPs. These accomplishments have been made possible through the passage of the Developmental Disabilities Act and the interest of people like you, Senator Harkin, and your continuing interest in advocacy on behalf of the disabled.

We are confident that the proposed reauthorization will permit us to meet the complex and changing needs of persons with disabilities and their families.

Thank you, and I'll be happy to respond to questions.

[The prepared statement of Ms. Rhodes follows.]

## PREPARED STATEMENT OF ANN RHODES

Good morning. My name is Ann Rhodes and I serve as the Vice President of University Relations for the University of Iowa. I am here today representing our Nation's network of 57 University Affiliated Programs (UAP) authorized under the Developmental Disabilities Assistance and Bill of Rights Act.

Although the University of Iowa program serving children with disabilities was initiated over 45 years ago, it did not become a UAP until 1972. This affiliation permitted it to expand its vision from serving as a clinical evaluation and treatment unit to being a statewide and national training and information resource for people with disabilities. It has accomplished this by working cooperatively with the Iowa Developmental Disabilities Planning Council and the Iowa Protection and Advocacy Agency to create and ensure the availability of family and community resources that now support all Iowans with disabilities to achieve their goal of living independent lives in their own homes and communities.

The Iowa program is fortunate in receiving a direct state appropriation to support much of their clinical program. But, Senator Harkin, you and your colleagues need to be aware that the two-hundred-thousand dollar allocation received by the Iowa UAP from the Federal Administration on Developmental Disabilities to support its core administrative responsibilities permits the program to leverage additional program dollars. There is solid evidence that for every dollar invested in a UAP there is a \$28 return on that investment through expanded services and training programs. The Developmental Disabilities Act's core funding permits each UAP to operate at such a high level of efficiency.

Any university would be proud of such solid accomplishments from one of its units. There can be no doubt there are 56 other universities that take similar pride in their UAP accomplishments.

However, Senator, as you are aware, true satisfaction only comes when a job has been completed. We are far from the day when all persons with disabilities can feel similar pride in their roles as productive independent members of communities of their choice. Provisions in the draft reauthorization would permit UAPs to be more efficient and effective in accomplishing these tasks. We ask that you and the committee consider the following proposals in the draft reauthorization language.

The proposed reauthorization includes a significant update of the definition of a UAP. Specifically, this new definition supports current activities that are at the heart of a university's mission: the interdisciplinary preservice preparation of students and postgraduate trainees; dissemination of research findings; assisting in the discovery and transfer of technology into community settings; and to assist community human, health, and education services personnel and systems to reflect state-of-the-art knowledge. These activities, when compared to the mission of a university, reinforce the original wisdom of Congress to place these responsibilities regarding the needs of people with disabilities solidly in the heart of America's university system.

Unfortunately, the tasks outlined above have only been partially completed. A critical shortage remains in the availability of appropriately trained personnel including occupational therapists, physical therapists, nutritionists, doctors and nurses. A fundamental change is occurring in university training programs to shift the training emphasis from service delivery in segregated settings toward training professionals to work in partnership with individuals with disabilities and their families in their own communities.

Senator Harkin, prior to assuming my current responsibilities at the University of Iowa, I had the privilege of serving as the nursing supervisor for the Department of Pediatrics in University Hospitals. We treated on a daily basis numerous children with a variety of severe disabilities. However, only too frequently, we saw children return to our relatively high priced tertiary care center for medical care when that same service could have been provided in a less costly community-based hospital. The training models now used in UAPs permit our future therapists, nurses and physicians to understand and provide quality care in the communities in which people with disabilities live.

In addition, contemporary support systems call for technical assistance services to be available at the community level. For many UAPs, it is the technical assistance activities, as opposed to the provision of direct services, that has had the greatest impact on ensuring that state and local service delivery systems can adequately respond to the needs of individuals with disabilities.

We feel there are four key priorities in the reauthorization. Specifically, the draft reaffirms our central priority of securing a program in every state. Thanks to you, Senator Harkin, we now have 57 UAPs in 49 states and 2 territories. Only Wyoming and the Virgin Islands remain unserved.

Second, the bill places the priority at securing a training project at every eligible UAP. The Iowa UAP recently completed a two year training program that prepared nine-hundred direct care workers to effectively provide supports and services to people who behave destructively toward themselves. This project barely made a dent in the need for such statewide training in Iowa. Our next training project will train people with disabilities to serve as their own advocates, so they may effectively communicate with public and private policy brokers and decision makers. We anticipate the program will provide two-hundred and fifty people per year such proactive abilities.

In addition, we are extremely pleased that the bill adds the Americans with Disabilities Act (ADA) to the areas of training, which we hope will facilitate meaningful and long-term implementation of this landmark legislation. Thanks to your leadership, the ADA is now the law of the land, and its principles provide the foundation for all our activities.

Once the two previously mentioned priorities are satisfied, the bill recommends increasing the training project award from \$90,000 to \$100,000. The final priority in the bill is to increase the UAP core award from \$200,000 to \$250,000.

In summary, Mr. Chairman, the Iowa UAP is proud to report on its accomplishments which are representative of the entire network of UAPs. These accomplishments have been made possible by the foresight of Congress in creating the Developmental Disabilities Act. We are confident the proposed reauthorization will permit us to better meet the complex and changing needs of individuals with developmental disabilities and their families.

We thank you for the opportunity to share these views with you today and I would be pleased to respond to your questions.

Senator HARKIN. Ann, thank you very much for being here.

Dr. Healy, did you have anything to add at all?

Dr. HEALY. I would just bring together a number of the these that have been expressed here this morning by relating one incident that recently happened at the university.

I think there is a theme of optimism coming through this morning, that things are changing, that the results of the variety of pieces of legislation that you have personally been involved with is bringing a greater array of supports to persons with disabilities, including the ADA.

Recently I had the opportunity of presenting grand rounds at the department of pediatrics and chose as my subject the Americans with Disabilities Act. Usually, grand rounds is somewhat meagerly attended, and the subjects of infectious disease and cardiac problems draw a meager audience.

The subject of the Americans with Disabilities Act brought essentially a standing room audience, and the participation and the questioning and the interaction of the guests was very impressive.

Senator HARKIN. When was this? How long ago?

Dr. HEALY. About 4 months ago. And it was not only increasing their technical awareness of what they had to do as pediatricians to comply with the law, but the interests in their advocacy roles and what their attitudinal changes needed to be came through very strongly.

I thought you would enjoy hearing that these are all coming together in a very positive way.

Senator HARKIN. Very good.

Again, I want to thank you all for your willingness to meet with my staff and the staffs of Senator Durenberger, Senator Kassebaum and other members of the subcommittee. I appreciate everyone working together. It is, again, a reflection of my belief that we do this in a coordinated and comprehensive manner.

Mr. Eidelman, in your prepared statement, you discuss the theme of interdependence. We have been stressing this for a long

time, cooperation and coordination among the three program components at the State level. We required that UAPs and P&As be members of the DD councils; that DD councils and P&As be members of the UAP consumer advisory committees. We have tried to bring all of this together.

I hope we have made some progress in this. What else do you see out there that needs to be done in terms of this kind of coordination?

Mr. EIDELMAN. I think the structural basis, Senator, is in place. At this point, you would have to be able to regulate good will and common sense, and I don't think the U.S. Senate can do that.

If there is some way to get in each State the senior leader of a Governor's administration to pay more attention to the interrelationships, I think that would go a long way, whether it is a cabinet official or a Governor's chief of staff or policy chief, to bring these people together and work on these issues. But I am not sure legislation or regulation is going to make it work. I have seen it work splendidly in two States and not very well in another, and it was purely personality-driven.

Ms. WIGGINS-MITCHELL. Senator Harkin, if I could comment on that as well, I think one of the factors may be leadership from the administration on developmental disabilities, both here in Washington and through the regional office. And I can think of a very concrete example of where that has happened in the area of diversity, encouraging collaboration and cooperation in achieving diversity throughout the DD system. As a result of the first annual commissioners' forum on multiculturalism and diversity in the State of New Jersey, we have in fact set up a cooperative, statewide team involving the DD council, the UAP and the protection and advocacy system, to try and reach out to underserved and unserved populations, not just minorities, but rural populations as well as individuals who have other than English as their primary language.

So we have set up a task force, and just a couple weeks ago, our UAP had an all-day forum in which they brought in a consultant on diversity, and the statewide task force met with the consultant, and he served as our facilitator and gave us some direction.

So I think there is hope. I think it is happening. It takes an awful lot of hard work and commitment on the part of all of us. But I agree, I think the structure is there, but I think the leadership is key. And I also should mention our regional office last year called a meeting of the three sister agencies, and we went to New York and had some discussion—in fact, Andy, I do believe you were a part of that—around the various programs. And they are doing that again this year in August, and hopefully with input from the three programs, we will make it more the kind of form that we want it to be. So I think it is happening.

Senator HARKIN. Mr. Porter, why are we continuing to have problems with the State allotments for the basic State grant program and the P&A program—even when we have had increased appropriations sometimes the States cut it.

Mr. PORTER. Senator, I think it is easier to understand the theory of relativity than it is to understand that formula. We looked at it at the national level, and I looked at it specifically in Illinois, and 1992, when we had a 5 percent increase, Illinois got one per-

cent, and when we went down one percent last year, we went down 3.5 percent. So there doesn't seem to be any rhyme or reasons. And not only that—ADD will publish the figures 1 day, and then 3 days later tell you those figures are wrong and give you another set of figures. So even they have trouble figuring out what it is. It's one of those things that rather difficult to define.

I think your draft, saying first of all that we should be held harmless—and I prefer, of course, 1992 levels because those are the highest levels for Illinois—would work and give ADD time to study this process, because it just doesn't work. Under the rehabilitation act and the client assistance program, their formula doesn't cause all of these deviations. So it definitely needs more study.

Senator HARKIN. Well, that's what we put in the draft, and a hold harmless clause.

Mr. PORTER. Well, the council supports that wholeheartedly.

Senator HARKIN. That's strange. I can't understand it, either.

Mr. PORTER. I don't know who can, honestly.

Senator HARKIN. Well, we have to work up a new one, there is no doubt about that.

Ann, in your testimony, you say the fundamental change in training programs is to shift the training from service delivery in segregated settings toward training professionals to work in partnership with individuals in their own settings and their own communities.

Again, I am obviously very pleased to hear that we are training people to understand self-determination and choice. What kinds of strategies are you going to employ to achieve this? Obviously, it's a new way of thinking, it's a new approach. Before, it was easy, because you had a segregated, institutionalized-type setting. Now you have diversity out there. How do you train someone for that?

Ms. RHODES. I think there are two points I'd like to make in response to that. One is to pick up on something that some other witnesses were alluding to, and that is that children growing up in the school system now are exposed to people with different levels of ability in a way that they weren't when I was growing up, so it is not something that is hidden, and people are aware of this throughout the educational process, and I think this is positive. People are aware of the potential of persons with disabilities because they have grown up with them. I think this gives people a mind set that people in my generation did not have because the kids weren't in school with us, frankly.

In terms of education and educating people to focus on advocacy and primary care, you have to start early, early in the educational process. And it is an example of something that needs to be built in as a fundamental premise of the things that you teach, for example, health care providers about.

Speaking to my background as a nurse, this is the kind of thing that needs to be introduced early as a principle that you learn how to support.

Senator HARKIN. Would it be safe to say that it is going to be more difficult to train professionals now, or not?

Ms. RHODES. It will be more challenging. I think the thing that it is going to require is something else that you've been talking about, which is coordination and integration. It will require clinical

practicum in different kinds of settings. You won't have a patient base just sitting there, waiting for you to put your students there to learn about it. You will have to be a little more creative about getting your students into community centers and things like that. It is an exciting challenge, I think, for an educator.

Senator HARKIN. Now, there you go. You were here earlier, I'm sure, when I talked about using the Iowa communications network, the new fiberoptic network, for that. This sounds like an excellent opportunity to use that in terms of training professionals.

Ms. RHODES. Yes, I believe that's something that we are already thinking about. But that's an excellent point.

Senator HARKIN. Well, I'd like to be helpful in that, if I could.

Ms. RHODES. Thank you.

Senator HARKIN. I'm trying to understand all the different things that we can start loading up on this network right away, and this might be one. In terms of educating people on the ADA itself, this is a different slice of it here, in terms of training the professionals. It could be done.

Ms. RHODES. That's a good point. One of the things I do in my role at the University of Iowa is I've been involved in getting the University of Iowa into full compliance with the ADA, and one of our challenges is getting everyone out there in a very large and diverse institution to know what their responsibilities are. And when you look at a statewide issue, it of course becomes even greater. But we are looking at all of the different ways of communicating this, including the telecommunications system, to get the information out. So that's an excellent point.

Senator HARKIN. Good.

Well, again, I thank you all for being here, and unless somebody has something they want to add for clarification or anything like that, thank you again for being here.

The subcommittee will stand in recess subject to call of the chair.

[Whereupon, at 12:35 p.m., the subcommittee was adjourned.]